


COVID-19 Pandemic: Mental Health in Girls With and Without Fragile X Syndrome

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Abstract

Objective Children and adolescents, who have less developed coping skills, are affected by natural disasters and other traumatic events differently than adults. Emotional and behavioral effects are particularly pronounced during a pandemic-related disaster, when support networks that typically promote healthy coping, such as friends, teachers, and family members, may be less available. Children and adolescents with fragile X syndrome (FXS), who are at increased risk for developing anxiety and depression, may be particularly vulnerable to behavioral or emotional difficulties during a pandemic. This study examined the mental health outcomes of school-aged girls with FXS during the COVID-19 pandemic and associated stay-at-home orders. **Methods** Participants included 47 school-aged girls with FXS and 33 age- and developmentally matched comparison girls. Associations between COVID-19 behavioral and emotional outcomes and prior academic, adaptive, behavioral, and emotional functioning as well as prior maternal mental health and characteristics of the mother–child relationship were examined. Qualitative data from the parental report of emotional and behavioral responses to the pandemic were also obtained. **Results** Results indicate that school-aged girls with FXS demonstrate a distinct profile of COVID-19 related associations compared to the comparison group, such that pandemic-related worries and emotional impact of pandemic restrictions were predicted by prior mental health factors for the comparison group but by prior social, behavioral, and relational factors for the FXS group. **Conclusions** Findings provide insight into factors that may confer risk or resilience for youth with special needs, suggesting potential therapeutic targets and informing public health initiatives in response to the pandemic.

Key words: anxiety; COVID-19; intellectual disability; parent psychosocial functioning; parent–adolescent communication; school functioning; school-age children; social functioning and peers.

Introduction

Children and adolescents, who have less developed coping skills, may suffer from greater stress and trauma than adults after experiencing a disaster (Lazarus et al., 2003; Roussos et al., 2005; Shen et al.,

2020). Common responses to traumatic events and disasters in children include anxiety, depression, and impaired social interaction (Hoven et al., 2005; Laor et al., 1997; Park et al., 2020). A supportive family environment and parental modeling of healthy coping

skills can serve as strong protective factors for children's postdisaster mental health (Cobham et al., 2016; Schofield et al., 2013). Although there is a growing body of literature describing children's responses to trauma, disasters, and adverse events in general, investigations of children's responses to pandemics in particular remain relatively sparse (Klein et al., 2018).

While pandemics have much in common with other types of disasters in terms of community impact, unpredictability, fatalities, and persistent effects, the response differs because individuals are actively discouraged from engaging in activities that promote social support such as group gatherings (Sprang & Silman, 2013). Although pandemic isolation measures may help quell an outbreak, they can have unintended consequences of inhibiting family rituals and disrupting routines that usually enhance family functioning and foster resilience in crises. Accordingly, pandemic-associated isolation can increase the potential for adverse outcomes (Fiese & Spagnola, 2007; Luthar, 2015). Previous pandemics such as H1N1 and SARS negatively impacted mental health in youth, with up to 30% of isolated or quarantined children meeting the criteria for PTSD (Masten & Obradović, 2008; Sprang & Silman, 2013). There was a strong association between clinically significant PTSD symptoms in parent respondents and their children, suggesting a link between parent and child mental health (Sprang & Silman, 2013). Pandemic-related home confinement, school closures, and lifestyle changes can cause disruption of emotional support provided by teachers, other adults, or peers (Sprang & Silman, 2013).

Recent studies examining mental health effects of the COVID-19 pandemic have shown significant psychosocial impact on youth, with reported increases in anxiety, depression, and behavioral problems (Marques de Miranda et al., 2020; Viner et al., 2020). One study conducted with children 3–18 years of age in the Shaanxi province of China demonstrated that the most common behavioral problems were distractibility, irritability, and clinginess towards parents (Jiao et al., 2020). Young children (3–6 years) were more likely to show clinginess towards parents and fear of family members being infected, while older children (6–18 years) were more likely to experience inattention and persistent question asking (Jiao et al., 2020). With regard to internalizing symptoms specifically, children exhibited higher levels of anxiety and depression than prior to the pandemic (Chahal et al., 2021; Duan, 2020). Similar to observations during previous pandemics, children of parents with anxiety symptoms had greater emotional and behavioral problems (Liu et al., 2021).

One of the principle measures taken to curb the spread of the pandemic has been closure of schools and recreational areas, resulting in reliance on

distance learning and reduced opportunity for physical activity and socialization (Singh et al., 2020). The absence of the traditional school environment has disrupted educational plans and routines that are essential for young people (Jiao et al., 2020). Greater smartphone and internet usage as well as decreased physical activity during the pandemic were associated with increased anxiety and depression in youth (Chen, 2020; Duan, 2020; Liu et al., 2021). The extent of mental health impacts may depend on vulnerability factors such as developmental age, special needs, pre-existing mental health, and parental health status (Jones et al., 2020; Marques de Miranda et al., 2020; Singh et al., 2020).

Youth who are predisposed to developing anxiety or receive special education services may be at increased risk for adverse mental health effects in response to the pandemic. One such group is children and adolescents with fragile X syndrome (FXS). FXS, the leading genetic cause of autism and intellectual disability, is associated with a significantly increased risk for developing anxiety and depression (Bailey et al., 2008; Cordeiro et al., 2011). Because the disorder is X-linked, females generally show a milder cognitive phenotype than males, though many demonstrate significant developmental, behavioral, and social-emotional challenges (Bartholomay et al., 2019; Loesch et al., 2003). Mothers of children with FXS are often carriers of the fragile X premutation, which is associated with increased risk for experiencing anxiety, depression, and interpersonal sensitivity (Gossett et al., 2016). As such, school-aged girls with FXS may be differentially impacted by the COVID-19 pandemic.

In this study, we assessed the mental health effects of the COVID-19 pandemic among girls with FXS and age- and developmentally matched girls. Parents completed online questionnaires to assess their daughter's pandemic-related worries and the emotional impact of pandemic restrictions. We examined associations between pre-pandemic academic, adaptive, and social-emotional functioning and current response to the pandemic. Given previous links between postdisaster mental health of parents and their children, we examined associations between prior maternal mental health and child response to the pandemic. To our knowledge, this is the first study to examine the mental health impacts of the COVID-19 pandemic among school-aged girls with FXS.

Methods

Data were collected as part of a longitudinal study supported by the National Institute of Health examining cognition, behavior, and neurodevelopment in school-aged girls with FXS and their sex-, age-, and

developmentally matched peers (see Bartholomay et al., 2019; Miller et al., 2021 for preliminary findings from this larger study). Full mutation FXS diagnosis was confirmed by molecular genetic testing (>200 CGG repeats in the FMR1 gene). Participants with FXS were recruited through the National Fragile X Foundation, regional FXS organizations, Fragile X Online Registry With Accessible Research Database, Stanford FXS registry, and social media announcements. Comparison subjects were recruited through advertisements with California Regional Centers, schools, and parent organizations. Individuals were excluded if they were born very preterm (<30 weeks), exhibited major sensory deficits (i.e., significant hearing or vision deficits that would have interfered with the child's ability to fully participate in neurodevelopmental testing), or had confirmed diagnosis of uncontrolled seizure disorder, psychosis, or bipolar disorder. English was the primary language spoken by all participants. A total of 80 participants (FXS $N=47$, mean age = 11.9 years, range = 6.3–18.0; Comparison $N=33$, mean age = 12.2 years, range = 8.2–16.6) who underwent neurodevelopmental assessment during their initial study visit subsequently completed supplementary questionnaires to assess response to the COVID-19 pandemic (81.0% completion rate in the FXS group and 71.7% completion rate in the comparison group). Pandemic-specific questionnaires were completed from May 2020 through July 2020, and families were asked to respond based on the child's functioning in April 2020. See Table I for demographic characteristics and Figure 1 for disruption in support services. All procedures were carried out in accordance with the latest version of the Declaration of Helsinki and were approved by the Stanford University Institutional Review Board. Informed consent was obtained from each parent/caregiver, and informed assent was obtained from each participant.

Initial Prepandemic Study Visit

Assessments completed during the initial, prepandemic study visit included measures of academic achievement, adaptive skills, child mood and behavior, parental mental health, and characteristics of the parent–child relationship. For consistency, only maternal mental health and relationship ratings were utilized. We included the following measures to assess the broad range of core areas potentially impacted by FXS (see Supplementary Table 1 for detailed descriptions): (1) Academic and adaptive functioning: Kaufman Test of Educational Achievement, Third Edition Brief Form (KTEA-3 Brief) and Vineland Adaptive Behavior Scales, Third Edition (Vineland-3); (2) Social functioning: Social Responsiveness Scale, Second Edition (SRS-2); (3) Child mood and behavior: Child Behavior Checklist (CBCL) Parent Form, and

Anxiety, Depression, and Mood Scale (ADAMS); (4) Maternal mental health: Symptom Checklist-90, Revised (SCL-90R); and (5) Mother–child relationship: BASC-3 Parenting Relationship Questionnaire (BASC-3 PRQ).

Follow-up Assessments during the Pandemic

Pandemic-specific measures were collected from May 2020 through July 2020. The supplementary battery assessing response to the pandemic was adapted from The CoRonaVirus Health Impact Survey (CRISIS), Parent/Caregiver Form. The CRISIS was developed through a collaboration among the National Institute of Health (NIH), Child Mind Institute, and Nathan Kline Institute (Nikolaidis et al., 2021). This multiple-choice survey captures the impact of life changes associated with the COVID-19 pandemic on mental health and behavior (e.g., sleep, physical activity, time outdoors, worries, mood, and media usage). We selected relevant questions and specified that parents should consider April 2020 when responding. For more information about the original CRISIS, visit <http://www.crisissurvey.org/>.

We created two index scores as our primary outcome variables: (1) Pandemic-related worries: child's worries about being infected, friends or family members being infected, physical and emotional consequences of the pandemic, and frequency of asking questions, reading, or talking about the pandemic; and (2) Impact of pandemic restrictions: the emotional impact of stay-at-home restrictions, difficulty adhering to restrictions, changes in contact/relationships with others, and/or family financial status (see Supplementary Table 2 for survey items and scoring). In addition to multiple-choice items, parents were given two opportunities to provide comments about their daughter's response to the pandemic, reaction to distance learning, and parental concerns. Two researchers who were blind to the participant group independently identified common themes across participants' responses. These two researchers then compiled their lists of common themes across responses, removing redundant themes and reconciling any differences in identified themes through discussion (see Figure 2 for themes). These two researchers then recoded the original participant responses using the newly established list of common themes to ensure that all responses were captured with a theme. These two researchers then jointly trained four additional researchers, who were also blind to the participant group, to the coding scheme of assigning themes to each response. A total of six researchers completed the coding for the qualitative themes (two initial researchers and four additional trained researchers). If a theme was identified by at least four of the six researchers

Table 1. Demographic Characteristics of Sample Including Participants’ Age, Verbal IQ, Adaptive Behavior, Autism Symptomatology, Race, Number of School- and Community-Based Supports Disrupted by the Pandemic, Percentage of the Sample with At least One Family Member Who Identifies as an Essential Worker, and Type of Residential Area

	FXS (n = 47)	Comparison n = 33)	p-value
Age, mean (SD)	11.84 (3.11)	12.23 (2.25)	.60
Race (percentage of sample)			
White	89.36	54.54	
Black	2.13	0	
Asian	4.25	24.24	
More than one race	4.25	21.21	
DAS-II verbal ability	78.27 (17.96)	87.64 (18.20)	.03
Vineland-3 adaptive behavior composite	80.52 (12.72)	79.48 (11.79)	.71
ADOS-II classification (percentage of sample)			
Nonspectrum	52.27	63.64	
Autism spectrum	11.36	6.06	
Autism	36.36	30.30	
COVID-19 related factors			
Supports and services ^a	2.60	2.64	
Essential worker in household ^b	43%	38%	
Residential area (percentage of sample)			
Large city	8.51	9.09	
Suburbs of a large city	40.43	39.39	
Small city	19.14	27.27	
Town or village	17.02	12.12	
Rural area	8.51	0	

^aAverage number of school- or community-based supports and services (e.g. speech/language therapy, physical therapy, occupational therapy, social skills group, tutoring, after-school sports team or club, etc.) disrupted due to the COVID-19 pandemic.

^bPercentage of families with at least one family member living who identifies as an essential worker living in the home.

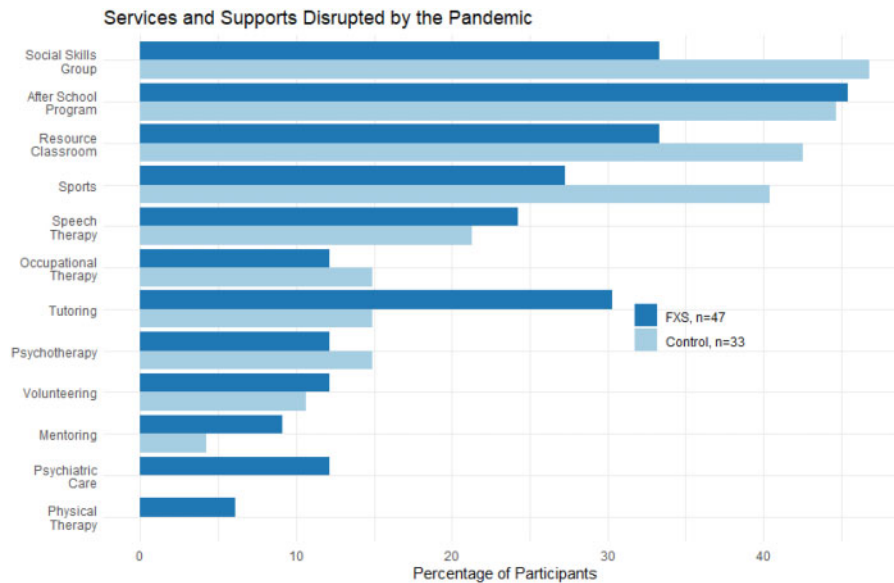


Figure 1. Proportion of each group that experienced disruption in educational and social-emotional supports during the pandemic based on parent report. Values indicate the percentage of participants within the group (FXS or comparison) who experienced disruption.

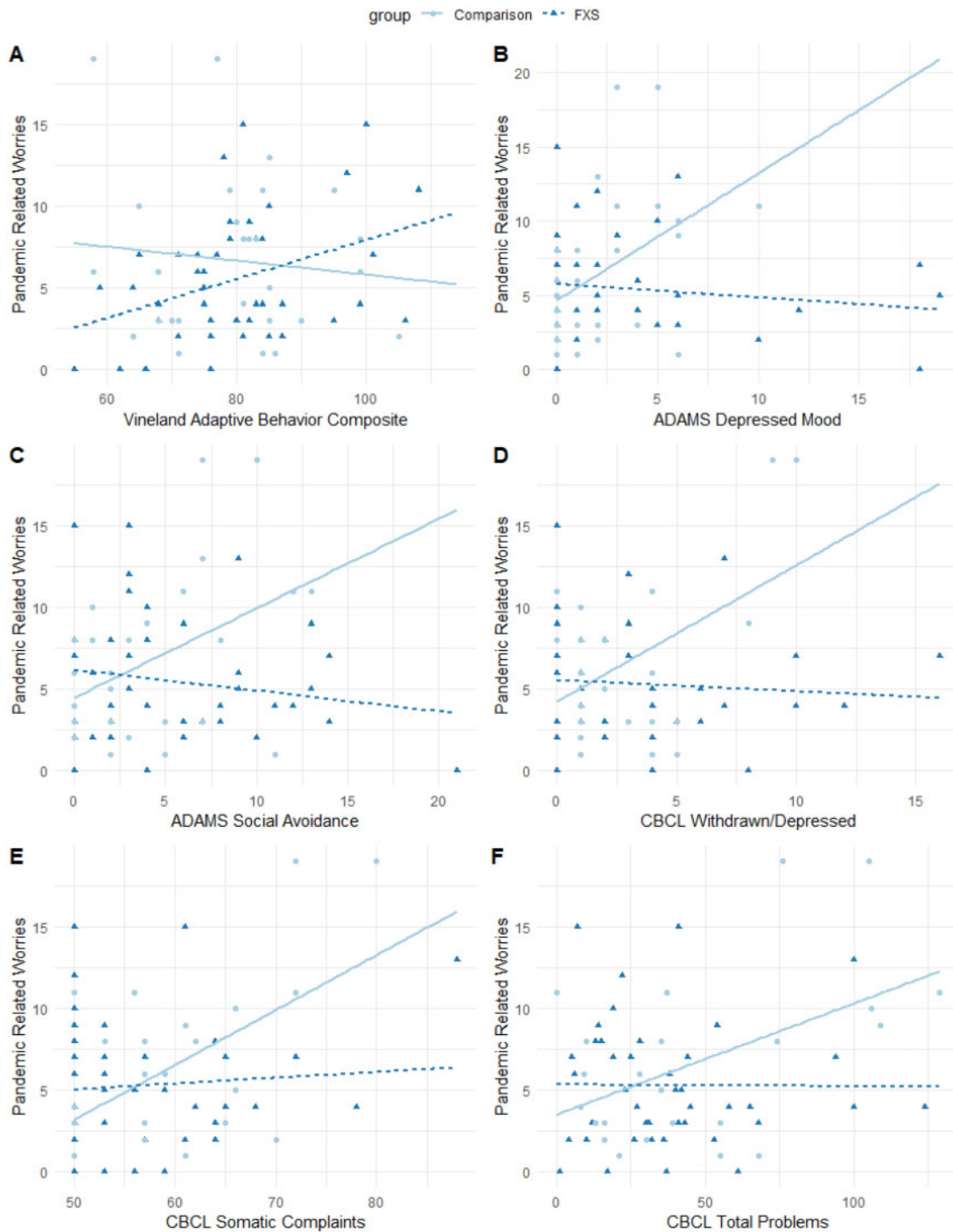


Figure 2. Qualitative themes observed in parents’ responses regarding their child’s response to the COVID-19 pandemic.

(≥67% consensus), that theme was assigned for the qualitative analyses.

Analyses

All quantitative data were analyzed using SPSS, Version 27. One-way ANOVAs with verbal IQ (DAS-II Verbal Ability) entered as a covariate were used to assess between-group differences for pandemic outcome variables (pandemic-related worries and impact of restrictions). Pearson correlations were conducted

to examine associations between pre-pandemic functioning (academic achievement, adaptive and social functioning, child’s mood and behavior, maternal mental health, and characteristics of the mother–child relationship) and emotional/behavioral functioning during the pandemic (pandemic-related worries and impact of restrictions) within each group (FXS and comparison group). Fisher r-to-z transformations were performed to determine if the correlations were significantly different between groups. To determine if

underlying group differences in verbal IQ may be driving group differences in correlations, *posthoc* sensitivity analyses were conducted by removing four participants with the lowest verbal IQ in the FXS group to create verbal IQ-matched groups. Pearson correlations were then conducted for the same variables as described above.

Power Analyses

Using G*Power 3.1 software examining the strength of the correlations in the primary analyses, the achieved power ranged from 0.7 to 0.85.

Results

Pandemic-Related Worries

There was no significant group difference in pandemic-related worries when controlling for verbal IQ ($F(1,63) = .190, p = .664$). Within the FXS group, prior adaptive functioning (Vineland-3 Adaptive Behavior Composite, $r(40) = .38, p = .014$) and parent-child relationship characteristics (PRQ Communication, $r(37) = .39, p = .014$; Involvement, $r(37) = .42, p = .008$; Frustration, $r(37) = -.33, p = .040$) were predictive of pandemic-related worries with higher adaptive functioning, greater parental interaction, and less parental frustration associated with more worries (see Table II and Figure 3). Within the comparison group, prior academic functioning (KTEA-3 Brief Achievement, $r(24) = .45, p = .021$), child's mental health (ADAMS Depressed Mood, $r(26) = .44, p = .019$, Social Avoidance, $r(26) = .44, p = .018$, and General Anxiety, $r(26) = .49, p = .008$; CBCL Withdrawn/Depressed, $r(31) = .47, p = .025$ and Somatic Complaints, $r(31) = .52, p = .011$), child's overall mood and behavior (CBCL Total Problems, $r(21) = .49, p = .017$), and maternal mental health (SCL-90 Depression, $r(26) = .39, p = .041$ and Phobic Anxiety, $r(26) = .39, p = .043$) were predictive of pandemic-related worries, with greater prior mental health challenges being associated with more pandemic-related worries. Remaining domains for each measure were not significantly associated with pandemic-related worries for either group ($p's > .05$). When examining group differences using Fisher r-to-z transformation, correlation strengths were significantly different between the groups for Vineland-3 Adaptive Behavior Composite, ADAMS Depressed Mood and Social Avoidance, and CBCL Withdrawn/Depressed, Somatic Complaints, and Total Problems ($p's < .05$). For ADAMS Depressed Mood, ADAMS Social Avoidance, CBCL Withdrawn/Depressed, and CBCL Total Problems, the FXS group showed a negative correlation with pandemic-related worries while the comparison group showed a positive correlation with pandemic-related worries. Vineland-3 Adaptive

Behavior Composite was positively correlated with pandemic-related worries in the FXS group and negatively correlated with pandemic-related worries in the comparison group. CBCL Somatic Complaints were positively correlated with pandemic-related worries in both groups, with the comparison group demonstrating a significantly stronger positive association.

Impact of Pandemic Restrictions

When controlling for verbal IQ, there was no significant group difference in the impact of pandemic-related restrictions ($F(1,63) = .599, p = .442$). The impact was significantly negatively correlated with aspects of social functioning (SRS-2 Social Awareness, $r(41) = -.38, p = .013$; Communication, $r(41) = -.32, p = .039$; Total Score, $r(41) = -.32, p = .036$) for the FXS group but not for the comparison group, such that greater social dysfunction prior to the pandemic was associated with reduced impact of COVID-19 restrictions for the FXS group (see Figure 4). The impact of the pandemic was significantly positively correlated with ADAMS General Anxiety for the comparison group ($r(26) = .45, p = .018$), but not for the FXS group, indicating that higher pre-pandemic anxiety was associated with greater impact of pandemic restrictions. Remaining domains for each measure were not significantly associated with pandemic-related worries for either group ($p's > .05$). Fisher r-to-z transformation revealed significantly different correlation strengths between groups for SRS Social Awareness, Communication, and Total score ($p's < .05$), such that there was a negative correlation for the FXS group and a positive correlation for the comparison group.

Post-Hoc Sensitivity Analyses

After removing four participants with the lowest verbal IQ from the FXS group, there was no significant between-group difference in verbal IQ ($p = .139$). Within the FXS group, prior adaptive functioning (Vineland-3 Adaptive Behavior Composite) and parent-child relationship characteristics (PRQ Communication, Involvement, and Frustration) remained significantly correlated with pandemic-related worries. Within the comparison group, prior academic functioning (KTEA-3 Brief Achievement), child's mental health (ADAMS Depressed Mood, Social Avoidance, and General Anxiety; CBCL Withdrawn/Depressed, Somatic Complaints, and Total Problems), and maternal mental health (SCL-90 Depression and Phobic Anxiety) remained significantly correlated with pandemic-related worries. The impact of pandemic restrictions remained significantly negatively correlated with SRS-2 Social Awareness; however, SRS-2 Communication and SRS-2 Total Score were no longer significantly correlated for the

Table II. Statistically Significant Associations Between Prepandemic Measures and Subsequent Pandemic-Related Worries and Impact for Each Group

	FXS		Comparison		Fisher r-to-z transformation p-value
	Pearson correlation	p-value	Pearson correlation	p-value	
Association with pandemic-related worries					
Academic and Adaptive					
Vineland-3 adaptive behavior composite	.38*	.014	-.11	.595	.040*
KTEA-3 brief achievement	.21	.188	.45*	.021	.262
Child mood and behavior					
ADAMS depressed mood	-.12	.431	.44*	.019	.014*
ADAMS social avoidance	-.17	.291	.44*	.018	.008**
ADAMS generalized anxiety	.11	.476	.49**	.008	.080
CBCL withdrawn/depressed	-.07	.669	.47*	.025	.018*
CBCL somatic complaints	.09	.594	.52*	.011	.046*
CBCL total problems	-.01	.965	.49*	.017	.026*
Maternal mental health					
SCL-90 depression	.21	.193	.39*	.041	.430
SCL-90 phobic anxiety	.08	.647	.39*	.043	.178
Mother-child relationship					
PRQ communication	.39*	.014	.03	.877	.116
PRQ involvement	.42**	.008	.17	.379	.272
PRQ frustration	-.33*	.040	-.01	.950	.174
Association with impact of pandemic restrictions					
Social					
SRS-2 social awareness	-.38*	.013	.26	.212	.006**
SRS-2 communication	-.32*	.039	.25	.248	.018*
SRS-2 total	-.32*	.036	.25	.234	.016*
Child mood and behavior					
ADAMS general anxiety	.10	.508	.45*	.018	.114

*p < .05;

**p < .01.

FXS group. For the comparison group, impact remained significantly positively correlated with ADAMS General Anxiety.

Qualitative Themes

Parents were provided two opportunities to provide qualitative commentary. For the first opportunity, 41 parents (87.2%) in the FXS group and 30 parents (90.9%) in the comparison group provided a response. For the second opportunity, 11 parents (23.4%) in the FXS group and 13 parents (39.4%) in the comparison group provided a response. Across both the groups, increased anxiety, emotional changes, and lack of social opportunities were the most commonly reported parental concerns (see Figure 4). Four parents (8.5%) in the FXS group and three (9.1%) in the comparison group described their daughters as experiencing heightened anxiety and difficulty coping with stay-at-home orders. Three parents (6.5%) in the FXS group and two (6.1%) in the comparison group reported depressed mood and increased sensitivity during the pandemic. One mother in the FXS group disclosed, “She is emotionally sensitive to more things, friends not wanting to talk, not being allowed to socialize.”

With regard to adapting to pandemic restrictions, the most prominent themes were school-related frustration, difficulty transitioning to distance learning, and lack of structured routine. Eleven parents (23.4%) in the FXS group and 12 (36.4%) in the comparison group expressed frustration with distance learning. Moreover, 16 parents (34.0%) in the FXS group and 13 (39.4%) in the comparison group described their daughters as having difficulty adjusting to the lack of structure in their daily routine. One mother described, “It was a very difficult transition... We suddenly changed the learning environment (home), mode of learning (assignments online when she is not used to using the internet/computer) and, of course, the teachers (me in place of eight teachers).” Comparison group parents described similar frustrations. One mother noted, “Zoom fatigue is so real for her! On the days she has lots of services she is SO DONE before the end of the day... We are exhausted together.”

Six parents (four in the FXS group and two in the comparison group) highlighted positive aspects of the pandemic. Specifically, several parents in the FXS group reported that their child learned new skills and improved her ability to use technology. One mother

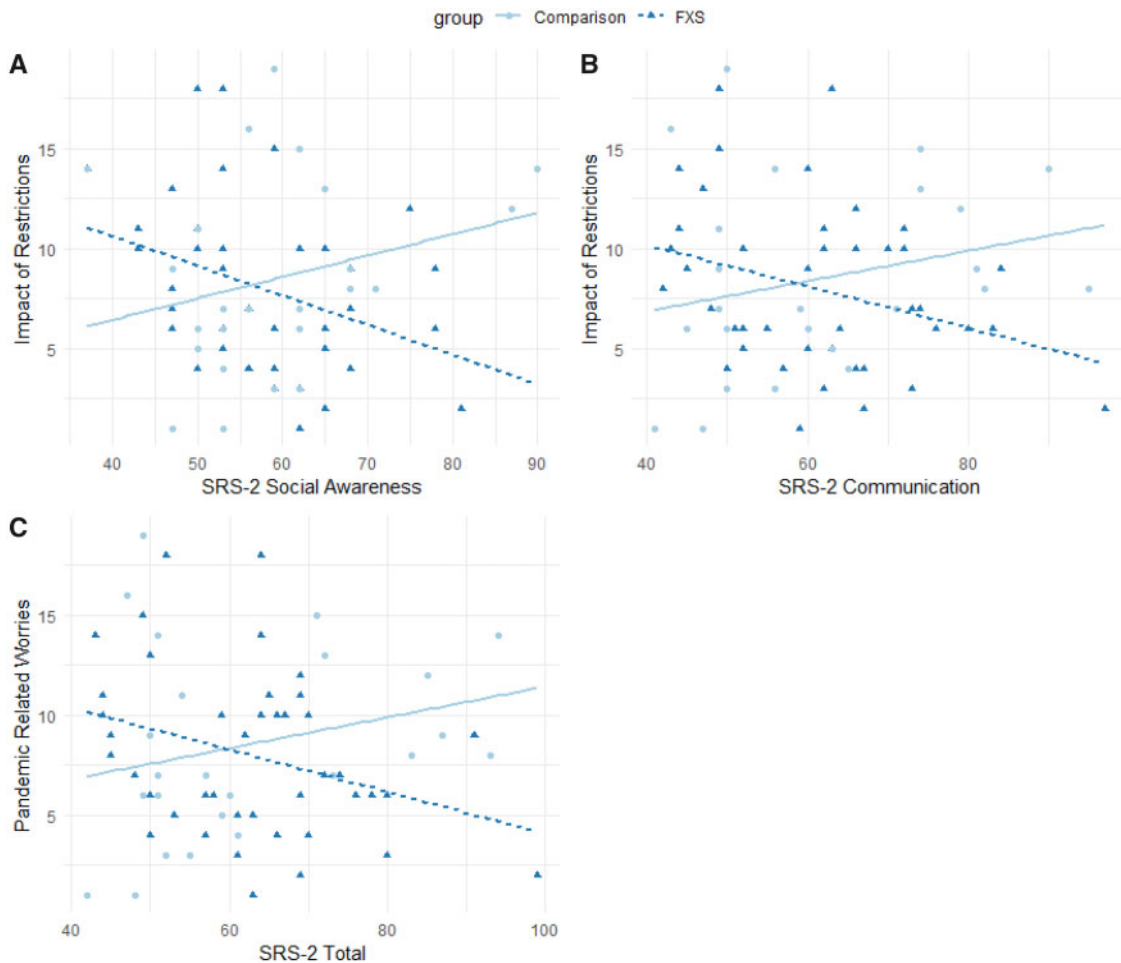


Figure 3. Associations between pre-pandemic measures and pandemic-related worries with significantly different Fisher r - z correlation strengths between the FXS and comparison groups.

explained, “there are a lot of positives in her use of technology, particularly in that it is something she does as well or better than typical peers. She can follow instructions from a YouTube video to construct a house of favorite TV characters in Minecraft, counting spaces and following directions independently, when formal Math is extremely challenging.” Another parent in the FXS group described the new skills her daughter learned, stating, “in nearly all arenas, technology consumption has allowed her to stay connected and express herself much more clearly than she tends to do orally.”

Discussion

We investigated the impact of the COVID-19 pandemic on emotional well-being and behavior in school-aged girls with FXS and sex-, age-, and developmentally matched peers. Preliminary studies examining mental health effects of the pandemic have suggested that children with special needs and predisposition to mental health challenges, such as girls with

FXS, may be at increased risk for developing symptoms of anxiety, depression, and behavioral problems in response to the pandemic (Jones et al., 2020; Marques de Miranda et al., 2020; Singh et al., 2020). As such, we examined associations between prior functioning and current response to the pandemic, with the goal of identifying factors that may confer risk or resilience. We utilized data from a larger, pre-pandemic longitudinal study to capture prior functioning and invited the same participants to complete supplementary questionnaires to assess functioning during the pandemic. Given the link between parental and child mental health following other disasters (Sprang & Silman, 2013), we explored potential aspects of prior maternal mental health and the mother–daughter relationship associated with youth’s response to the pandemic. Distinct patterns of associations between pandemic mental health outcomes and prior functioning, maternal mental health, and aspects of the mother–daughter relationship emerged for the two groups. Specifically, pandemic-related worries and the emotional impact of pandemic restrictions

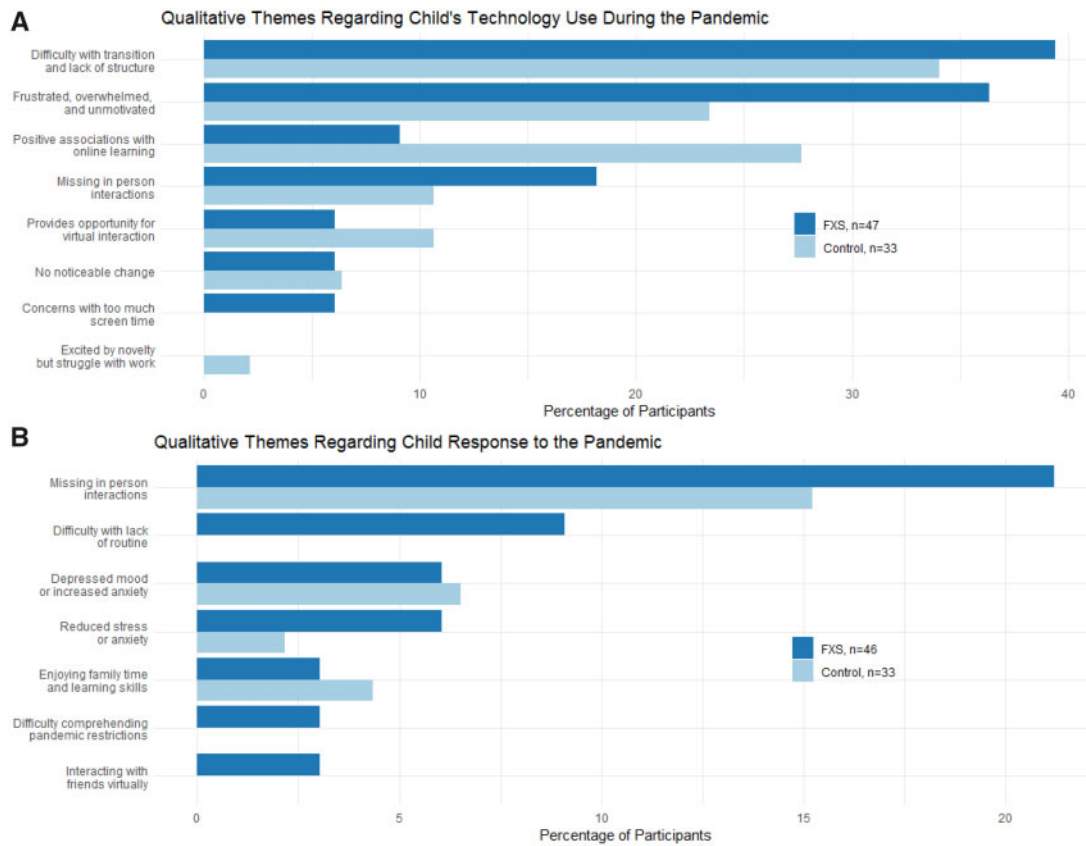


Figure 4. Associations between pre-pandemic measures and impact of pandemic restrictions with significantly different Fisher r-to-z correlation strengths between the FXS and comparison groups.

were predicted by prior mental health factors for the comparison group but by prior social, behavioral, and relational factors for the FXS group.

For pandemic-related worries, child’s prior academic achievement and emotional functioning were predictive of outcomes for the comparison group, whereas prior adaptive functioning and characteristics of the mother–daughter relationship were predictive for the FXS group. For the comparison group, higher-achieving students may experience more worries about how academic changes during remote instruction will influence their learning trajectory. In contrast, students with prior academic challenges may benefit from the more individualized pace and increased parental involvement during remote learning. As expected, more symptoms of generalized anxiety, depression, somatic complaints, and overall behavioral problems prior to the pandemic were associated with greater pandemic-related worries for the comparison group. Greater pre-pandemic social avoidance, which is a core feature of social anxiety in children and adolescents (Hitchcock et al., 2010), was associated with pandemic-related worries. This finding was somewhat unexpected given previous commentaries that socially anxious children may experience relief during the pandemic due to reduced exposure to anxiety-provoking

situations at school and in the community (Morrisette, 2021). However, social anxiety also commonly co-occurs with other anxiety disorders in children and adolescents (Kendall et al., 2010). We hypothesize that girls who were rated as having greater pre-pandemic social avoidance also experienced greater pre-pandemic anxiety more broadly, which is predictive of pandemic-related worries. Similar to what other groups have observed in typically developing children (Liu et al., 2021; Sprang & Silman, 2013), greater pre-pandemic maternal depression and phobic anxiety were also predictive of pandemic-related worries in the comparison group. Overall, girls in the comparison group who displayed more emotional and behavioral dysregulation prior to the pandemic, as well as girls with mothers who endorsed more symptoms of depression and phobic anxiety, experienced greater worries during the pandemic.

Somewhat unexpected, the same social-emotional and behavioral associations with pandemic-related worries were not observed for the FXS group. Rather, prior characteristics of the mother–daughter relationship and adaptive functioning were the strongest predictors of worries. In the FXS group, prior maternal communication and involvement were positively correlated with pandemic-related worries, while prior maternal frustration levels

were negatively correlated with worries. Our results are not consistent with previous studies showing that parents' open communication with their children during the COVID-19 pandemic led to better outcomes for typically developing children (Jiao et al., 2020), and this discrepancy highlights the key differences in how girls with special needs, and with FXS specifically, may be impacted by the pandemic. For girls with FXS, a high level of maternal interaction may be a potential risk factor, rather than a protective factor, for the child's pandemic-related worries such that highly involved, communicative mothers may inadvertently transfer their worries to their daughters. Our findings highlight the importance of maternal awareness of one's own emotions, as well as shifts in routine during the pandemic, and how this may impact children. Instead of increasing communication and providing children with more information about the pandemic, our results suggest that parents of girls with FXS should focus on modeling effective coping skills and maintaining a consistent routine to minimize pandemic worries (Singh et al., 2020). In addition, parents should continue to allow opportunities for their daughter to retain independence in their daily activities to minimize emotional impact.

When considering the perceived impact of the pandemic restrictions, reduced physical contact with people outside the home, and cancelation of important events, more than one-third of parents from both groups qualitatively described their daughters' challenges with adjusting. However, when considering predictors of impact, the two groups exhibited distinct patterns of associations similar to those observed with pandemic-related worries, with emotional factors being predictive for the comparison group and behavioral factors being predictive for the FXS group. Specifically, prior generalized anxiety was associated with pandemic impact for the comparison group. As expected, girls with greater anxiety symptoms prior to the onset of the pandemic experienced greater distress associated with pandemic restrictions. However, this association was not present in the FXS group. Rather, challenges with social awareness, communication, and overall social functioning were negatively correlated with the impact of restrictions. This suggests that girls with FXS who had weaker social skills experienced the less negative impact of the stay-at-home orders. One hypothesis for this relationship is that girls with FXS who have weaker social skills experience discomfort and anxiety in social situations despite being interested in friendships (Hong, 2019) and, therefore, experience relief with social pressure and complexity of in-person interactions lifted during the pandemic. As such, these individuals may experience less negative impact from pandemic restrictions. One parent in the FXS group noted that her daughter, who has social skills challenges, benefited from pandemic restrictions

in that she was able to communicate more effectively in writing compared to typical in-person social interactions. Meanwhile, girls with FXS who have relatively stronger social skills may experience a greater sense of loss with the cancelation of events and reduced in-person interactions. Parents can offset these impacts by helping their children maintain positive peer connections, encouraging ongoing communication with peers by text message or phone call, and creating virtual social opportunities during stay-at-home orders (Singh et al., 2020).

We acknowledge some limitations to this study. Although pandemic-related surveys were sent to all families enrolled in the initial longitudinal study, participation in this supplemental study was voluntary, and only a proportion of participants responded. Accordingly, the results were obtained from a relatively small sample size. Despite efforts to recruit a diverse sample, a larger proportion of participants in both groups identified as White, which may limit generalizability to individuals of other backgrounds. Although questionnaires were made as accessible as possible by offering them online, families who experienced significant physical, emotional, or financial hardship during the pandemic may have been unable to complete them. While we designed the supplementary surveys to capture the child's mood and behavior in April 2020, when most states were under the strictest stay-at-home orders, the results represent only a snapshot in time within the pandemic. This study sample may not be completely representative of pandemic responses worldwide given the heterogeneity in regional pandemic-related restrictions, and caution must be used when generalizing our findings more broadly.

In conclusion, the current study examines the effects of the COVID-19 pandemic and stay-at-home orders on 47 school-aged girls with FXS and 33 age- and developmentally matched girls. The FXS and comparison groups demonstrated differential profiles of associations between pre-pandemic factors and pandemic outcomes. Worries about the COVID-19 pandemic and the impact of stay-at-home orders were significantly associated with prior emotional functioning for the comparison group but associated with social and adaptive behavior for the FXS group. This pattern of relationships suggests that the response of girls with FXS to the pandemic is distinct from girls without FXS, which provides insight into how families of girls with FXS may minimize the negative effects of the pandemic. Future studies may investigate the long-term effects of the pandemic on youth.

Supplementary Data

Supplementary data can be found at: <https://academic.oup.com/jpepsy>.

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