



# HHS Public Access

## Author manuscript

*Am J Speech Lang Pathol.* Author manuscript; available in PMC 2020 July 17.

Published in final edited form as:

*Am J Speech Lang Pathol.* 2006 November ; 15(4): 353–364. doi:10.1044/1058-0360(2006/033).

## Communication in Young Children with Fragile X Syndrome: A Qualitative Study of Mothers' Perspectives

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### Abstract

**Purpose:** The purposes of the study were to provide descriptive and qualitative information about communication in young children with fragile X syndrome (FXS) and about how families react to and accommodate communication differences in their children.

**Method:** In-depth interviews were conducted with 55 mothers of young children with FXS. Interviewers asked mothers to describe their children's communication, strategies they used to help promote their children's communication, communication-related frustrations, their expectations for their children and the roles that they perceive for themselves.

**Results:** Over half the children were nonverbal and learning to communicate with augmentative or alternative communication (AAC). Mothers reported using strategies that were developmentally appropriate and recommended by early childhood experts, such as reading and talking to their children. Many mothers identified challenges faced in helping their child to communicate, and some cited difficulty obtaining speech-language services as a challenge. Mothers identified their roles as caregiver, teacher, therapist and advocate.

**Conclusions:** The perspectives offered by mothers are valuable because they indicate how children with FXS communicate in natural contexts. Information about mothers' expectations and roles may help clinicians to be sensitive to variables that will impact working with young children and their families.

Fragile X syndrome (FXS) is the most common inherited cause of mental retardation, resulting in significant impairments in development and adaptive function (Crawford, Acuna, & Sherman, 2001; Turner, Webb, Wake, & Robinson, 1996). FXS affects 1 in 4000

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males and 1 in 6000 females of all races and ethnic groups (Centers for Disease Control, 2005). Males with FXS usually exhibit moderate to severe intellectual impairment, a range of language difficulties, and social and behavioral difficulties, including problems with attention, impulsivity, anxiety, and arousal (Cohen et al., 1988; Dykens, Hodapp, Ort, & Leckman, 1993; Kerby & Dawson, 1994; Reiss & Freund, 1992). As many as 25-35% children with FXS also meet the diagnostic criteria for autism (Bailey, Hatton, & Skinner, 1998; Dykens & Volkmer, 1997; Hagerman, 2002). Females are usually less severely affected, tend to score in the mild to average range of intellectual function, and display milder but characteristic patterns of social anxiety and challenges in executive function as well as language delays commensurate with their cognitive level (Abbeduto et al., 2003; Fisch et al., 1999; Hessl et al., 2001; Keysor & Mazzocco, 2002; Lesniak-Karpiaik, Mazzocco, & Ross, 2003; Mazzocco, 2000; Mazzocco, Baumgardner, Freund, & Reiss, 1998).

## Communication Development in Fragile X Syndrome

Children with FXS often have delays in their development of communication (Abbeduto & Hagerman, 1997; Roberts, Mirret, Anderson, Burchinal, & Neebe, 2002; Roberts, Mirrett, & Burchinal, 2001). Studies of adolescents and adults show distinct patterns of speech and language development, with males being more severely affected than females (Abbeduto & Hagerman, 1997). Moderate to severe delays have been reported in all aspects of language development including expressive and receptive vocabulary, syntax and pragmatics (Fryns, Jacobs, Kleczkowska, & Van den Berghe, 1984; Newell, Sanborn, & Hagerman, 1983; Roberts et al., 2001; Sudhalter, Scarborough, & Cohen, 1991). In addition to language delays, speech intelligibility in conversation is often poor (Paul, Cohen, Breg, Watson, & Herman 1984; Spinelli, Rocha, Giacheti, & Richieri-Costa et al., 1995). Pragmatic deficits may include perseverative speech and poor topic maintenance (Belser & Sudhalter, 2001).

Very little is known about communication development in *young* children with FXS, however. It has been reported that most children with FXS eventually learn to speak, but the onset of speech may be severely delayed (Lachiewicz & Mirrett, 2000). Roberts and colleagues (2001) studied 39 boys with FXS ranging in age from 20 to 86 months and found that children's receptive and expressive language development was markedly delayed, yet there were considerable individual differences. The boys' receptive language tended to develop faster than their expressive language over time. The children's cognitive skills and autistic characteristics predicted the boys' receptive and expressive communication development. In another study of 22 boys with FXS ranging in age from 21 to 77 months and who were verbal, Roberts and colleagues reported on the strengths and weaknesses in early communication development (Roberts, et al., 2002). Vocal and verbal developments were relative strengths compared to gesture use, reciprocity, and play skills. Children who scored higher in communicative functions, vocalizations, verbalizations, and reciprocity scored higher in language comprehension one year later. Two other recent studies of preschool children found children with FXS and autism scored lower in receptive and overall language and expressive language than children with FXS who did not have autism (Philofsky, Hepburn, Hayes, Hagerman, & Rogers, 2004; Rogers, Wehner, & Hagerman, 2001).

## Communication in authentic contexts

There remains a need for additional information about the range of communication in young children with FXS. Information about communication in everyday interactions with family members is typically not reported in standard research or clinical reports. Information about the communication strategies employed by young children with FXS and their caregivers would be very useful for both families and professionals. Families often question professionals and other parents about expected development for their children and there is currently little information available to convey. In addition, information about communication in everyday interactions can be extremely beneficial to speech language pathologists (SLPs) and other professionals planning home-based interventions.

In the case of a child younger than 3 years old, SLPs often work with parents to try to enhance a child's opportunities for learning communication within the contexts of daily life. For example, parents of a child with disabilities are often taught to recognize and respond to children's communication attempts (Girolametto, Verbey, & Tannock, 1994), or to emphasize specific vocabulary during interactions (Girolametto, Weitzman, & Clements-Baartman, 1998). These recommendations were developed for children with other types of disabilities such as Down syndrome, but may also be appropriate for children with FXS particularly given a clearer understanding of their early naturalistic communication styles and abilities. To date, there have been no reports of early communication interventions specifically for children with FXS.

### Parent report measures.

Parents provide a wealth of information about their children's communication. In fact, parent report measures have become primary sources of information about children's communication development (Dale, 1996). Many assessments rely on parent report to identify possible delays and disorders in speech and language development (e.g., Bzoch & League, 1991; Fenson et al., 1993). Compared to standardized tests, parent report measures can often provide more extensive information about children's communication in everyday contexts (Boudreau, 2005; Dale, 1996). Parent report is also the best means to obtain information about parents' opinions about their children's communication.

In light of the shortage of information about communication in young children with FXS, we felt it was important to share the information gained from interviewing mothers of young children with FXS. As investigators in a longitudinal study on development in young children with FXS, we had access to in-depth parent interviews that asked parents about many aspects of raising a child with FXS, such as the mother's perception of the children's temperament, behaviors, and communicative abilities; parental expectations for the child's development; parental strategies for promoting development and learning; family roles, relationships and supports; and understandings of FXS. These interviews also included specific questions about their child's communication and it is the answers to these questions we report in this paper.

The information for this article comes from in-depth parent interviews, often referred to as ethnographic interviews. Ethnographic interviews can provide information about

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communication in authentic contexts (Damico & Simmons-Mackie, 2003); can be used to investigate people's perceptions about their communication or the communication of those with whom they frequently interact; and can contribute to understanding and treating the holistic nature of a communication disorder (Brinton & Fujiki, 2003). We relied on interviews in the current investigation to gain information about the range of communication abilities observed at home by mothers of young children with FXS, the challenges faced by mothers while interacting with these children at different stages of communication development, and the various strategies parents use to promote their child's communication development.

## Method

### Participants

The study participants were 55 biological mothers of young boys (n= 44) and girls (n= 11) with full mutation FXS. Families were recruited across all 50 states from genetics clinics, pediatricians' offices, and developmental clinics. All families were participating in a larger, longitudinal study of family adaptation to raising a child with FXS. For the present study, we analyzed data from all families in the study who had a child that was 3 years of age or younger at the time of the first parent interview.

**Maternal characteristics.**—Mothers were diverse in terms of age, education, income, and state of residence. The average age of the mothers at the time of the interview was 32.2 years, with a range of 20 to 41 years. Mothers had an average of 15.2 years of education with a range of 8 to 19 years. Only three of the mothers had less than a 12<sup>th</sup> grade education. Twelve of the families were categorized as low-income, defined as having an annual household income less than 200% of the federal poverty threshold. Families resided in one of 22 states. Families were less diverse on the basis of ethnicity/race, with 52 mothers reporting their ethnicity as white, 2 as African American and 1 as Latino. Regarding marital status, 47 of the mothers were currently married, 4 had never been married, 2 were divorced, 1 was separated, and 1 was eng{Brady, in press #1666}d. With few exceptions, the mother was the child's primary caregiver. We recruited only families of children with full mutation FXS, so given the transmission patterns of FXS, we knew that in all cases the mother either was a carrier of FXS or had the full mutation herself. Of the 55 mothers, 41 were carriers, and 4 had the full mutation (the other 10 either had not been tested or the test results were not available).

**Child characteristics.**—The average number of siblings in each family was 1.1 (SD = 1.1) with a range from 0 to 5. In 17 families, the study child was the only child. For 4 families, the study child was the oldest child. In 3 families (s)he was the middle child, and for 31 families (s)he was the youngest child.

Cognitive development was measured by a trained staff member who administered the *Mullen Scales of Early Learning* (MSEL; Mullen, 1995) to each child within a week of the parent interview. The children's mean score on the *Early Learning Composite* (standard score) was 57.5 with a range from 49 to 101. The composite score combines scores from subtests on receptive language, expressive language, fine motor, gross motor and visual

processing. The composite score is based on a standardized mean of 100 and standard deviation (SD) of 15. Participating children's mean score on the *Mullen Expressive Language Composite* (T score) was 26.5 (range from 20 to 51), and their mean score on the *Mullen Receptive Language Composite* (T score) was 25.4 (range from 20 to 55). The composite T scores are based on a standardized mean of 50 with a SD of 10.

**Grouping of participants.**—While the information from the MSEL is interesting in terms of comparing children's development to typically developing children, for the current study we were most interested in mothers' descriptions of how their children with FXS communicate in real, ongoing interactions. Each mother was asked to describe their child's language and communication skills. Mothers' descriptions were extensive, and allowed the four authors to categorize the children into three groups by consensus: Twenty-nine children were described as Nonverbal. Nonverbal children were reportedly not producing any words, or were only producing words in imitative contexts. Emerging Verbal children were producing a few spontaneous words or other symbols, but mothers reported that they still relied on nonverbal means of communication such as gestures and nonspeech vocalizations to communicate. Thirteen children were described as Emerging Verbal. The Verbal group consisted of 13 children who reportedly communicated primarily through speech and were often producing sentences. The mothers' descriptions corresponded to our data from language sample analyses completed with each child around the time of the interview. The median mean length of utterances for each group were as follows: 0 (Nonverbal); 0.78 (Emerging Verbal); and 1.59 (Verbal).

The breakdown of child ages, and expressive and receptive age equivalent scores within each of these groups is presented in Table 1. Scores are broken out by gender because boys with FXS tend to be more severely affected by the disorder than are girls (Bailey & Nelson, 1995).

### Data Collection and Analysis

Mothers' perceptions of their child's communication abilities, and challenges and strategies related to communication were gathered using a semi-structured interview format (Patton, 1990). A qualitative methods approach was appropriate for exploring mothers' perceptions of communication issues and addressed a need for more qualitative research related to communication development and assessments (Damico & Simmons-Mackie, 2003; Simmons-Mackie & Damico, 2003; Tetnowski & Franklin, 2003). The interview protocol was designed by the research team, led by one of the co-authors (Skinner), who has experience in qualitative methodology and interviewing procedures (Skinner, Bailey, Correa, & Rodriguez, 1999; Skinner, Rodriguez, & Bailey, 1999). Questions elicited information on a number of domains of interest to the larger study, including the mother's perception of the child's temperament, behaviors, and communicative abilities; parental expectations for the child's development; parental strategies for promoting development and learning; family roles, relationships and supports; and understandings of FXS. One section of the interview protocol was devoted entirely to the subject of parents' expectations, concerns, and strategies related to the child's communication. Specific questions asked mothers to describe a) the child's communicative skills; b) strategies used to promote the child's communication,

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including strategies they reported learning from SLPs and strategies that facilitated understanding during episodes of misunderstanding; c) expectations for the child's communication; d) concerns, challenges, stresses, and frustrations regarding the child's communication; and e) their perceptions of their roles in relation to the child.. For example, one question related to strategies was "Do you have difficulty understanding what your child wants? If so, what do you do?" A more general question that assessed mothers' perceived roles was, "In general, what do you consider to be your roles and responsibilities in relation to (child's name)" (see Appendix A for Interview Protocol).

The semi-structured interview was conducted as part of a day and a half long assessment of the child and family, and averaged 90 minutes. Research assistants, intensively trained on conducting interviews and other assessments, interviewed mothers in their homes except in the few cases in which families opted to be assessed at the Frank Porter Graham Child Development Institute at the University of North Carolina at Chapel Hill. In most instances, the interview was done prior to other assessments as a way to get to know the family. Interviews were digitally recorded and transcribed word for word. For this study, we conducted a content analysis (described below) of the interview data relevant to the five main questions outlined above.

**Identification of communication statements.**—As an initial step before the content analysis, we compiled all data related in any way to perceptions of the child's communication abilities, expectations, challenges and strategies related to communication, and mothers' perceived roles. Two trained research assistants located all segments of text in the interviews related to these topics, summarized their content, and compiled these summaries for each mother. For the most part, mothers' statements were made in response to the specific questions on the interview protocol related to communication. Occasionally, mothers brought up communication issues at other points during the longer interview and these comments were also summarized.

**Coding of responses.**—The next step was a finer-grained coding of the compilations. Using a content analysis approach (Bernard & Ryan, 1998; Miles & Huberman, 1994), the authors together read all responses that had been compiled by the research assistants and created a thematic coding scheme that could subsume each response. For example, in the category of "mothers' strategies to promote the child's communication" statements such as "just constantly talking out loud to him," and "constantly having a conversation with him even though he does not answer" were subsumed by the theme "verbal input, talking to children" (see Table 2).

The coding scheme evolved through an iterative process, with categories being added or revised to fit the data. Once the coding scheme was finalized, the authors met together, but separately read each summary and coded each response. They then compared their coding. Initial agreement was over 90%. For those responses that were ambiguous or for responses for which authors did not agree on the initial code, we returned to the original data (the interview transcript), reviewed any additional contextual information that could help determine the appropriate category or code, and assigned the code through consensus.

The coding process resulted in a larger number of themes than are reported here. In the final analysis, we collapsed some themes that were similar, and report here only those themes for which 25% or more of the mothers in at least one communication group reported (see Tables 2-5). This process was similar to coding processes used to identify and classify themes from interview data in previous qualitative research (Baylor, Yorkston, & Eadie, 2005; Lyst, Gabriel, O'Shaughnessy, Meyers, & Meyers, 2005). The following Results section presents summaries of responses within each of the major topic areas: mothers' perceptions of their children's communicative abilities; strategies mothers reported using to facilitate communication development, including strategies that were specifically suggested by an SLP, and strategies to facilitate understanding their child; mothers' expectations for their children's communication; mothers' concerns, or expressed challenges regarding communication; and mothers' perceived roles for themselves.

## Results

### Summary of Children's Communication as Perceived by Mothers

Slightly over half of the children (29 out of the 55) were reportedly nonverbal. That is, their mothers reported that they did not use any words, signs or symbols to spontaneously communicate. As expected, the children in the Nonverbal group were for the most part younger than children in the other two groups and had lower MSEL age equivalent scores (see Table 1). The mean age for children classified as Nonverbal was 25.28 months compared to 28.31 months for children in the Emerging Verbal group and 34.38 in the Verbal group. The ranges of ages within the Emerging Verbal and Verbal groups indicate that some of the children, particularly girls, were closer to ages associated with these stages in typically developing children, while others were severely delayed in expressive and receptive language.

While most of the children were reportedly receiving some services from SLPs, many were not. Six children in the Nonverbal group, 3 children in the Emerging Verbal group and 2 children in the Verbal groups were not receiving services from an SLP at the time of the interview, according to mothers. The average numbers of hours per week of speech-language services reported for children in each group were: 1.4 (Nonverbal), 2.2 (Emerging Verbal), and 1.0 (Verbal).

### Strategies Mothers Use to Promote Children's Communication

Mothers reported that they engaged in a number of activities that they thought would promote their children's communication skills (see Table 2). Reading or looking at books as a way to promote their child's communication or language development was the most frequently mentioned strategy, and it was used by over two-thirds of all mothers. The majority of mothers also noted that they talked a great deal to their children, "bathing the child with words" as they went about their daily routines. One mother said about her nonverbal son, "We're just constantly talking out loud to him, whatever we're trying to do. Just so he can understand. It's repetition. The more he hears it, the more he probably will absorb it."

Nearly one-third of mothers of children in the Emerging Verbal and Verbal groups reported they asked their child to imitate productions. Approximately half of all mothers prompted verbal children to produce specific words, and about a third of these mothers also asked their child to expand on their child's utterance with a more advanced production. This strategy has been described as expansion (Owen, 1999; Roth & Worthington, 1996) and linguistic mapping (Cogher, 1999; Yoder, McCathren, Warren, & Watson, 2001). One mother gave the following example: "Like with books and stuff, I add words or if he says 'bye-bye' to something, and then I say, 'Oh, bye-bye cow'. You know, just trying to get him to add on that other word."

Augmentative or alternative communication (AAC) strategies such as sign language or Picture Exchange Communication System (PECS; Bondy & Frost, 1994) played a major role for three-fourths of the mothers of Nonverbal children. More than half of the mothers of Emerging Verbal children reported use of AAC compared to one-fourth of mothers of verbal children. As expected, AAC was reportedly used much less often for children in the Emerging Verbal and Verbal groups, while strategies which are more appropriate for children who are already producing some spoken words were reported to be used more often in these groups.

**Strategies suggested by SLPs.**—We searched the interview transcripts to identify instances where parents indicated they were using strategies specifically taught by their child's SLP. For the most part, these are the same strategies listed in Table 2. Most of these instances came in response to the direct question, "Based on your interactions or communications with the speech therapist, have you changed anything about the way you communicate with your child?" For example, one mother replied, "Oh yeah, everything I've learned has been from therapists cause I didn't have a clue. I barely knew how to be a mom!"

Some mothers commented that they appreciated being able to observe therapy because they then could try to use the observed teaching strategies at home. According to one mother, "I'm almost always observing the therapy or at least listening from the next room and it has a constant effect on how we interact with J, just trying to model those approaches."

Most of the mothers who indicated they were using AAC (e.g., sign language or PECS) with their child said they learned how to use these approaches from the SLP. One mother indicated that she "loved" her therapist for introducing PECS. A couple of parents indicated they were using these approaches even though their child's current SLP was focusing more on verbal productions. For example, one mother indicated she was implementing PECS with her child at home because she really liked it, but the child's SLP was working exclusively on sound production. Another mother indicated that she and her husband had taught their child to use sign language based on information in a book and a CD. According to this mother, the child's SLP told her to draw more attention to how she moves her mouth while speaking and discouraged the mother from accepting the child's signs as communication.

One mother's experiences with two different AAC systems led to the following observation. Based on the SLP's recommendations, the mother had taught her older child to use PECS

with the symbols placed on refrigerator magnets. The mother was now signing with her younger son. She reported,

With (older son) I always had on my refrigerator the magnets. We took pictures of everything around the house and (older son) would have to ask. He would have to give me what he wanted. We don't do that with (younger son) for a couple of reasons. The magnets would always get lost. They would never stay on the refrigerator. They would always fall down. Then they started eating them.

Mothers of children in the Verbal group indicated that, based on SLP recommendations, they used strategies such as simplifying the length of their utterances, speaking more clearly and using repetition. Some mothers also described SLP-recommended strategies intended to improve oral motor functioning. One mother commented that the SLP was very helpful in teaching her child to drink from a 'sippy' cup and in finding a nipple that her child would take. Another mother said she changed her methods of feeding her child because her SLP said that such changes could improve muscle tone.

**Mothers' strategies for helping their child to be understood .—**Communication breakdowns occur relatively frequently during the beginning stages of learning to talk, with some sources indicating as many as one in three child initiations are followed by a breakdown (Brady, 2003; Golinkoff, 1986). We were interested in how mothers negotiated episodes when their children were trying to communicate, but mothers could not understand these attempts. Mothers were asked, "Do you ever have difficulty understanding what your child wants? If so, what do you do?" Table 2 shows that mothers of 23% of the children on the Verbal group, 41% of children in the Nonverbal group and 69% of children in the Emerging Verbal group indicated that at these times, they tried to guess what their child was trying to communicate using trial and error (e.g., "I'll ask him, 'do you want this, do you want that?' I'll show him things until I figure out what he wants."). Requesting clarification was mentioned more by mothers of children whose verbal skills were emerging than by either of the other groups. As one mother illustrated, "I just ask him to repeat it. 'What did you say?' If I understand part of it, I'll say what I understand and then try to get him to tell me again."

Some mothers also noted that when all else failed, they would try to redirect or distract the child if they could not understand what the child wanted. A mother of a boy in the Nonverbal group gave an example:

"I just try a couple of different things and I either hit the right one or I distract him or he gets interested in something else and he kind of forgets, which is kind of sad, you know, if the little guy isn't getting what he wants."

### **Mothers' Expectations for their Child's Communication.**

Mothers' expectations for their child's communication differed somewhat depending on the child's current linguistic level (see Table 3). Mothers of children in the Nonverbal group focused their expectations more on their child's attaining any speech or communicative ability whereas mothers of children who had some speech, expressed expectations for their

child's improving speech and increasing vocabulary, such as speaking in longer sentences or using their communication to socialize more with peers.

For many mothers, reports of their expectations blended with hopes and concerns. For example, when asked about her current expectations and goals for her three-year-old son who was Nonverbal, one mother said,

Mostly – well, the thing I'm most worried about is his speech. So, I mean I'd love for him to just speak up one day and say a word. Just one word. And I guess that's my biggest goal is his speech. Because everything else seems to be coming along. And, to me he seems pretty normal with things. So, that's my hardest issue is his speech.

Three mothers indicated that they tried not to have many expectations for their child. One mother said,

I don't expect from him. You know, I just take it as a daily life because of his fragile X. But I expect kind of like more negative than positive... I don't expect him to be good in school, and I don't expect him to be in college or have a decent job or anything like that.

This mother followed up this comment by saying that she expected her child to always depend on her. That is, she foresaw her role as that of primary care provider for her child with fragile X and that this role would last forever.

### **Mothers' Concerns, Challenges, Stresses, and Frustrations Regarding their Child's Communication.**

Children's communication abilities were a major concern for many of the mothers. A statement by a mother of a child in the Nonverbal group encapsulates this concern, "I guess the most challenging thing is (his) not communicating now and I feel like if he could only say that word and tell me what it is he wants it would be so much easier."

Nearly one-third of the mothers of children in the Emerging Verbal group and one-fourth of the mothers of children in the Verbal group reported challenges associated with their child's communication skills. These challenges primarily centered on not being able to understand what the child wanted, frustrating both the mother and child. As one mother expressed, "It's a hard thing because it's just flat out he can't tell me what he wants." Another mother said, "It can get stressful when he's just constantly throwing himself down or something if he doesn't understand or can't communicate to us what he wants."

A few mothers discussed frustrations surrounding obtaining SLP services for their child. A mother of a 3-year-old child who was nonverbal and was still not receiving services elaborated,

"I've been fighting for speech for years. I kept saying, 'He's almost three, he has no language. Please give him speech.' Well, he tested receptively under 18 months so they won't give him speech unless he's 18 months cognitively, which I think is a stupid rule."

## Mothers' Perceived Roles

The responses by mothers in each group to the question, "In general, what do you consider to be your roles and responsibilities in relation to (child)?" are summarized in Table 5. Most of the mothers viewed their primary role as caregiver for their child with FXS, particularly mothers of nonverbal and emerging verbal children. But they mentioned other roles as well that coincided with the pervasive caregiver role. Some mothers expressed that they also saw one of their primary roles as carrying out the various interventions, or in ensuring that all appropriate interventions are provided. About one-third of mothers of children in the Nonverbal group saw themselves acting as the child's teacher and another third as therapist, while two-thirds of mothers of children in the Emerging Verbal group saw themselves as a teacher and a third of the mothers of the children in the Verbal group saw their role as a therapist. As one mother stated:

"I'm basically in charge of all of his therapy when he has therapy and bringing him down to (city name) and working with him on the feeding therapy stuff portion everyday... And that's more of my role and just putting into action what the therapists suggest that we work on and just making that a part of our lifestyle, a part of our routine... Bringing him to preschool and making sure that he is getting the therapies and the things that he needs to have in order to grow, to make progress."

Some mothers, however, indicated that they did not always embrace the roles of teacher, or therapist. This view was described by a mother of a child from the Emerging Verbal group,

"It's kind of sad in a way because everything I do with him is like a therapy-type thing and there's a lot of times I don't want to be that. I just want to be a mom. So it's hard for me sometimes to decipher between the two of them."

A relatively large proportion of mothers expressed that they saw their role as case manager or advocate, ensuring that they locate all useful information and services, and that appropriate interventions are provided. One mother said when asked about her roles:

"I'm everything. I feel like I'm the one that needs to – I feel like I'm the one that fights the hardest to get her in her services. Like with speech, she's met her goals. And, the speech evaluator said 'Well, I really don't feel that she needs the speech.' And, I said 'But, there's such a good chance that she could regress or that she could stop. And, I don't want to take that chance.'

In addition to these parental roles, several mothers viewed their role more broadly in terms of advocating for the needs of children with FXS. One mother, who was a regional coordinator for a fragile X parent group, stated, "Then the other thing that I think is my responsibility is to promote fragile X research and to be there for other families."

## Discussion

It is probable that SLPs and other related professionals will serve only a small number of children with FXS unless they work in a setting that specializes in treating FXS. Although FXS is the most common inherited cause of mental impairment and the most common known cause of autism, its occurrence is still relatively rare. Therefore, it may be difficult to

build expertise based solely on personal experience. Information from parents may be particularly important for professionals dealing with young children because parents are integral members of early intervention teams and interventions are often applied within the family contexts.

### **Reported Child Communication Levels and Speech Language Services**

We found a wide range of communication abilities reported by the children's mothers. Many of the children were reportedly nonverbal communicators, which is not unexpected considering the young chronological ages of children in our study and the developmental delays experienced by children with FXS. Children in the Nonverbal group were younger than children in the Emerging Verbal group, who were younger than children in the Verbal group. These differences in chronological ages between groups suggest that the children in each group may share a similar developmental trajectory, and that we sampled at different points along this trajectory.

Perhaps the most poignant statements in the interview were those that indicated the mothers' ardent desires for their children who were nonverbal or emerging verbal to learn to speak or communicate their needs. Parents reported using AAC with the majority of these nonverbal and emerging verbal children. Interestingly, several of the mothers indicated that they had taught their child to sign or use PECS without input from the child's SLP, or contrary to the advice of their SLP. These findings perhaps reflect a current trend to sign with all young children, even children without disabilities (Acredolo & Goodwin, 1996; Garcia, 1999). They also reflect the resourcefulness of parents and their willingness to seek information from various sources.

Many mothers provided examples of specific strategies that they learned either through explicit teaching by the SLP, or by observing the SLP during interventions. Although most parents were eager to help promote their children's communication in any way that they could, a couple of mothers lamented that their increased roles of teacher and therapist took time away from just being a mom. It may be helpful for SLPs to informally assess a parent's willingness before asking parents to take on additional duties such as teaching specific speech, language or feeding skills. For families that are willing and able to actively participate in therapy, assessments of families' priorities and routines should lead to identification of goals and methods that better fit individual family dynamics (Bruce, DiVenere, & Bergeron, 1998; Woods & Wetherby, 2003). Mothers may be more or less accepting of advice and suggestions depending on how they view their role in relation to their child's development. For example, some mothers felt very strongly that one of their primary roles was to advocate for the needs of their child, including appropriate services. These mothers wanted to be closely involved with planning their children's interventions.

A few parents indicated that their child's speech and language development was essentially normal and that they were no longer receiving any services by an SLP. However, other parents indicated a desire for speech-language services that were not available. The denial of services based on low cognitive skills reported by one mother is a violation of current recommended practices (American Speech Language Hearing Association, 2005; National Joint Committee for the Communicative Needs of Persons With Severe Disabilities, 1992).

Unfortunately, this statement attests to the persistence of outdated and invalid exclusionary criteria in some service delivery systems. Continued efforts are needed to dispel these exclusionary criteria and provide services based on documented needs of an individual child.

### **Developmental Differences Reflected in Mothers' Responses**

Most of the communication-promoting strategies mothers reported using with their children reflected recommended developmentally appropriate practices such as reading and talking to children. By separating our results according to communication levels, we were able to observe (cross-sectionally) differences in mothers' strategies, expectations, and perceived communication challenges that varied in accordance with children's developmental stages. For example, the strategies of expansions and prompting were reportedly used more often with children in the Verbal group than with children from the Nonverbal or Emerging Verbal groups. However, modified versions of these strategies have been developed for children with low-verbal skills (Tannock, Girolametto, & Siegel, 1992; Yoder & Warren, 2002). Parents may benefit from specific instruction in strategies such as linguistic mapping of nonverbal behaviors and prompting for gestures and vocalizations that developmentally precede speech or other symbolic communication modes. The importance of verbal input to children seems to be widely recognized, however. Mothers of children in all three groups were focused on verbal input and reading to their children-- both of which are highly recommended practices for young children (Dale, Crain-Thoreson, Notari-Syverson, & Cole, 1996; Hart & Risley, 1995).

Strategies used to facilitate understanding also showed a developmental shift. Mothers of verbal children often reported asking for clarification (e.g., "What?"), but mothers of nonverbal children rarely mentioned this strategy. It appears that mothers are more likely to use the strategy of requesting clarification when their child has some speech but may not be highly intelligible. This may be another area where parent education can improve interactions. Recent findings have shown that even nonverbal children frequently respond to requests for clarification (Brady, Steeples, & Fleming, in press). Mothers may assume that their children will not understand or will not be able to respond to requests for clarification, but this is seldom the case.

Children's developmental level or relative need also seemed to affect mothers' perceived roles and expectations. Higher proportions of mothers of children in the Nonverbal and Emerging Verbal groups described one of their roles as teacher compared to mothers of children in the Verbal group. It appeared that mothers of more advanced children did not feel as much need to take on the roles of teacher and therapist in addition to caregiver. Similarly, while mothers of nonverbal children expressed expectations regarding initial speech production, mothers of children who were talking expressed expectations for advancement in language areas such as vocabulary.

### **Experiences Specific to Families with FXS?**

For the most part, information reported in this study does not appear to be unique to families who have a young child with FXS. There are many observations common to families who have children with other developmental disabilities such as autism or Down syndrome

(Poehlmann, Clements, Abbeduto, & Farsad, 2005; Stoner et al., 2005). It may be helpful for SLPs and other practitioners to recognize similarities between children with FXS and other developmental disabilities. This suggests that knowledge and skills about communication development in general and communication development in children with disabilities will be applicable for assessing and treating many aspects of communication in young children with FXS. In addition, consideration of the family context is important for all children with disabilities, including FXS.

Knowledge about nonverbal communication may be particularly helpful for interventionists working with young children because of the high proportion of young children with FXS who were reported to be Nonverbal or Emerging Verbal communicators. It was interesting that while many parents described using AAC with their children who were nonverbal, only two parents mentioned working on nonsymbolic prelinguistic behaviors. One mother described working on eye contact and another mother mentioned working on pointing, based on recommendations from their respective children's SLPs. This suggests a need for increased education about the many forms of prelinguistic communication, including both symbolic and nonsymbolic forms.

### **Limitations and Future Directions**

A major limitation in the current research is the lack of diversity in some important aspects of the sample. Although FXS occurs equally among all ethnic groups, our sample was not representative of different ethnic groups in the United States. In addition, the number of girls in this study was too small to specifically analyze responses by mothers of girls or to compare responses for girls to responses for boys. Future research should attempt to include a diverse sample and more girls in order to identify any perceptions, expectations and strategies that may be identified by members of other groups.

The method of mothers' self-report in an ethnographic interview has some limitations. We were unable to verify mothers' descriptions of the strategies they reported with actual observations of their communicative strategies with the child. Direct observation would provide an additional layer of information. Also, although we probed for elaborated responses, we did not ask each mother directly about each theme listed in the tables. That is, we used an open-ended approach rather than a checklist. Thus, many of the responses should be interpreted as a conservative estimate. For example, mothers were not specifically asked if their child's communication was a challenge or concern. Instead, mothers were asked a general question about their concerns or challenges faced raising their son or daughter. Although this approach seems likely to identify mothers for whom communication was a primary concern or challenge, a checklist approach may have resulted in more mothers endorsing communication as a challenge.

In spite of these limitations, the qualitative and descriptive information presented in this study offers important information that should not only inform practice but also lead to more research on young children with FXS. A common theme running throughout the interviews was the lack of information currently available about this disorder in relation to child development. Parents and professionals would benefit from longitudinal studies that could provide information about the development of children with FXS, from the young ages

represented in the current study on into adulthood. In particular, research that helps clarify different developmental trajectories based on early characteristics is needed.

Finally, intervention research studies are needed to provide the evidence base for the many treatment approaches described in this paper as well as other approaches. Interventions such as increasing parent responsiveness to nonverbal and verbal communication, and increased verbal input through conversation and reading have been conducted with children with other disabilities and appear appropriate for children with FXS as well. Carefully documented interventions conducted specifically with children with FXS, however, may help identify modifications that specifically benefit these children and their families. Our findings suggest that interventions that incorporate family contexts and concerns will be highly valued by parents of children with FXS.

## Acknowledgments

Funding for this research was provided by NIH grants P30 HD003110-38S1 and P30 HD02528.

We wish to thank the dedicated staff who interviewed the parents and transcribed interviews, students who coded the transcripts, and most importantly the families who participated in this research.

## Appendix

### First Semi-Structured Interview Protocol

FXS Research Center: Family Adaptation to Fragile X Syndrome (Don Bailey, PI) UNC-Chapel Hill

#### Introduction:

For this interview, we are interested to hear more about what (child) is like, the expectations you have for (child), the strategies you use as a parent, and how FXS has impacted decisions you've made and your relationships with family members. There are no right or wrong answers to these questions. Every family's experiences and adaptations are different. We want to understand and document these different experiences and adaptations as a part of our study.

#### I. ABOUT THE CHILD

- I'd like to start by learning a little more about (child). Tell me about (child). What is he/she like?

[Probe for the topics below if not answered above, or probe to get more detailed descriptions]:

- What is his/her personality or temperament like (e.g., easy-going, happy)?
- How does he/she act around strangers?
- How does he/she act in new situations or settings?
- How is he/she with other children?

- Are there things that make him/her angry or frustrated? What? What do you do when this happens?
  - How is he/she at focusing on a task? Does this vary between home and school?
- We are also interested in how children communicate. How does (child) typically indicate when he/she wants something?
- What about if he/she doesn't want something? What does he/she do?
- Do you ever have difficulty understanding what your child wants? If so, what do you do?
  - Are there certain situations or times where your child has more difficulty communicating?
  - Are there differences in how your child communicates with you versus other members of the family? With other people outside of your family?
- What about times when you and your child just talk together about things? Could you give some examples of recent conversations—what they were about, when and where they typically take place? [For children who are nonverbal, ask]: Are there times you just talk to your child about things—carry on a conversation with him/her? Tell me about that? How does your child respond?
- [If the child receives speech therapy, ask:] Based on your interactions or communications with the speech therapist, have you changed anything about the way you communicate with your child? Please describe.
  - Probe: Is anyone teaching alternative means of communication such as sign language or a picture exchange system? If so, how does this affect your ability to understand your child?
- Are there times you read to the child? What kinds of things do you read to him/her? What is an example of a conversation you might have with the child about what you're reading?

## II. ABOUT PARENTAL EXPECTATIONS AND STRATEGIES

Transition: The next set of questions is about your expectations for (child) and the strategies you use as a parent.

- What expectations and goals do you have for (child) now?
- What kinds of things are you doing with (child) to help meet these goals? [You may need to repeat what the goals are.]
- Does this differ from the way you work with (target sibling)? In what ways?
- Are there other things you do to help (child) learn? Please describe.
- In general, what do you consider to be your roles and responsibilities in relation to (child)?

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**Table 1.**

Means (and standard deviations) of Child characteristics within each group

Characteristic	Nonverbal		Emerging verbal		Verbal	
	Boys n=25	Girls n=4	Boys n=10	Girls n=3	Boys n=9	Girls n=4
Chronological age (in months)	26.4 (9.5)	18.5 (7.9)	32.0 (4.4)	16.0 (7.0)	36.2 (.83)	30.2 (5.3)
MSEL expressive						
language age equivalent	9.2 (3.8)	9.8 (4.7)	16.8 (4.6)	11.7 (4.0)	24.7 (3.3)	25.2 (10.2)
MSEL receptive						
language age equivalent	11.8 (4.5)	10.8 (9.0)	16.10 (5.7)	11.7 (4.0)	22.4 (5.7)	22.8 (11.1)

<sup>a</sup>Only responses that were identified by at least 25 % of the mothers in at least one of the communication groups are included.

**Table 2.**

Strategies mothers reported to use to promote children's communication

Strategies	Percentage of mothers endorsing each strategy in each group <sup>a</sup>		
	Nonverbal	Emerging Verbal	Verbal
Reading/looking at books	79	69	69
Verbal input, talking to children	59	77	46
Augmentative or Alternative Communication (AAC)	76	62	23
Prompting child to produce words	10	23	54
Ask child to repeat or imitate Mom	7	31	31
Mom follows child's production with more advanced production (linguistic mapping)	0	0	31
Strategies to facilitate understanding:			
Mother guesses at what child is communicating/uses trial and error/gives choices	41	69	23
Mother requests clarification	10	46	23

<sup>a</sup>Only responses that were identified by at least 25 % of the mothers in at least one of the communication groups are included.

**Table 3.**

Mother's expectations for their child's communication

Expectation	Percentage of mothers endorsing an expectation <sup>a</sup>		
	Nonverbal	Emerging Verbal	Verbal
To communicate/speak	55	38	15
To have speech progress/learn more words	21	38	54

<sup>a</sup> Only responses that were identified by at least 25 % of the mothers in at least one of the communication groups are included.

**Table 4.**

Mother's concerns, challenges, stresses, or frustrations regarding their child's communication

Concern	Percentage of mothers expressing concern <sup>a</sup>		
	Nonverbal	Emerging Verbal	Verbal
Child's current communication or speech ability	14	31	23

<sup>a</sup>Only responses that were identified by at least 25 % of the mothers in at least one of the communication groups are included.

**Table 5**

## Mother's perceived roles

Role	Percentage of mothers endorsing each role <sup>a</sup>		
	Nonverbal	Emerging Verbal	Verbal
Caregiver	76	85	54
Teacher	34	62	15
Advocate	38	23	15
Therapist	28	8	31
Case manager/information seeker	14	31	23

<sup>a</sup>Only responses that were identified by at least 25 % of the mothers in at least one of the communication groups are included.