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Parent Reading Behaviors and Communication Outcomes in Girls With Rett Syndrome

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ABSTRACT: We describe evidence and intervention strategies for parents, educators, and researchers who seek to enhance communication and literacy in children with Rett syndrome (RS). Four girls with RS and their mothers videotaped their storybook interactions at home for 4 months. Parentchild storybook interactions were coded for child behaviors (e.g., use of augmentative communication devices, attention to book, or vocalizations) and parent behaviors (e.g., pointing in the book or asking predictive questions). Correlation and multiple regression analyses of these variables revealed that girls with RS can learn to communicate in meaningful ways through storybooks; however, mothers may need to engage in different strategies to facilitate better use of augmentative strategies. Successful strategies are discussed for the mother-daughter dyads.



ett syndrome (RS) is a pervasive developmental disability that is found almost exclusively in girls (one out of every 10,000 to 15,000) and

is marked by a gradual deterioration of hand use and language loss (American Psychiatric Association, 2000; Trevathan & Naidu, 1988). Some girls may retain a few single words, simple phrases or, even more rarely, sentences; but typically, girls with RS communicate by gestures, vocalizations, and body positioning (Coleman, Brubaker, Hunter, & Smith, 1988). Although first described by Andreas Rett in 1966, RS was not generally recognized as a medical disorder until 1983, when a second article was published (Hagberg, Aicardi, Dias, & Ramos, 1983). Since then, much progress has been made in identifying the genetic causes of RS (Amir et al., 1999; Clayton-Smith, Watson, Ramsden, & Black, 2000; Schwartzman et al., 1999; Sirianni, Naidu, Pereira, Pillotto, & Hoffman, 1998; Villard et al., 2001; Zappella, Meloni, Longo, Hayek, & Renieri, 2001), but little research has been done to cultivate communication and literacy in girls with this condition.

Some researchers suggest that girls with RS rarely communicate beyond a preintentional level

where caregivers assign meaning to the girls' behavior, but the children have no expectation or awareness that their caregivers will respond (Woodyatt & Ozanne, 1992, 1993, 1994). If the communication is successful, other researchers report that the dialogue is often inconsistent across tasks and occasions (Sigafoos, Laurie, & Pennell, 1995, 1996). However, recent intervention studies suggest that girls with RS can and may want to communicate at a deeper level. Splinting the nondominant hand, for example, resulted in the girls' purposeful use of their dominant hand to access a switch-activated augmentative communication device (Weiss, 1996). Girls with RS increased their requests for preferred foods using a computer with animated graphics (Van Acker & Grant, 1995) and successfully eyepointed to a named object when three picture communication symbols (PCS) were presented on a computer screen (Hetzroni, Rubin, & Konkol, 2002).

Previous studies have shown that through storybook readings, parents of children with significant disabilities were able to increase their child's spontaneous language use, verbaland picture-communication symbol use, and overall communicative performance.

In this study, 4 girls with RS and their mothers engaged in storybook readings, and we measured the level of interaction and communication that occurred between them. It is well documented that reading to children without identified disabilities can cultivate their language and literacy skills (e.g., Neuman, 1996; Strickland & Morrow, 1989; Teale & Sulzby, 1986), and we hypothesized that reading to children with RS would be no different. Previous studies have shown that through storybook readings, parents of children with significant disabilities were able to increase their child's spontaneous language use (Bellon, Ogletree, & Harn, 2000), verbal- and picture-communication symbol use (Dexter, 1998), and overall communicative performance

(Crowe, Norris, & Hoffman, 2000). Successful elements in these interactions have included parental acknowledgment of a child's competence (Koppenhaver, Evans, & Yoder, 1991), opportunities for the child to use multiple forms of communication (Coleman, 1991), and repeated readings of a familiar text (Bedrosian, Roberts, Neynaber, & Raap, 1995). Use of augmentative and alternative communication (AAC) devices can also improve literacy and verbal skills for children with speech and language disabilities, particularly those with autism (Charlop-Christy, Carpenter, Le, LeBlanc, & Kellet, 2002; Light, Roberts, DiMarco, & Greiner, 1998; Tjus, Heimann, & Nelson, 2001).

The present study was nested in a larger investigation on storybook reading at home as a context for early communication and emergent literacy intervention in girls with RS. We have previously reported that motivated parents did not require expensive technologies or lengthy training in order to enhance their child's communication and participation in storybook readings (Koppenhaver, Erickson, Harris et al., 2001). In a subsequent paper, we more fully examined the effects of resting hand splints, basic assistive technologies, PCS, and parent training on the nature and frequency of a child's communication during the reading of familiar and unfamiliar storybook texts (Koppenhaver, Erickson, & Skotko, 2001). We found that the girls with RS became more active and successful participants in storybook readings when both their nondominant hand was splinted and a single-message voice-output device was provided.

For this analysis, we asked: What is the relation between parental actions and the measures that we had previously reported for the children? For example, as a mother began to request more predictions and inferences, did the child's labeling and commenting increase? As the mothers became more directive, did the girls begin to use their switches more appropriately? When the mothers related story elements to the children's lives, did the girls pay more attention to the storybooks? We answer these questions and others, concluding the article with practical intervention strategies for parents and clinicians.

METHODS

PARTICIPANTS

Girls. Four girls (their real names used at the request of their parents: Amy, Baylee, China, and Petesie) with a primary medical diagnosis of RS participated in this study. The girls ranged in age from 3.6 to 7 years old at the onset of the study. All of them had severe communication impairment as evidenced by limited to no intelligible speech; nonconventional gestures (e.g., looking at people and objects) and vocalizations served as their primary mode of communication. Amy and Baylee ambulated independently, whereas China and Petesie required physical assistance such as hand-holding. All 4 girls engaged in various forms of repetitive hand-wringing, and all but Petesie further engaged in hand-mouthing behaviors. Amy and Baylee wore elbow splints for significant portions of each day, and Baylee and China were able to grab desired objects within reach. The parents reported that all 4 girls were believed to have normal hearing and vision, and their age-equivalent scores ranged from 5 to 19 months on the Bayley Scales of Infant Development (BSID-II; Bayley, 1993) and from 9 to 17 months on the Vineland Adaptive Behavior Scales (Sparrow, Balla, & Cicchetti, 1984). All 4 girls met the criteria for mental retardation established by the American Association on Mental Retardation (2002).

Mothers. Because all families agreed that the mother read more often with the daughter than did the father, mothers participated in this study. All mothers were Caucasian and reported that they read books with their daughters two or more times a week prior to their involvement in this study. None of the mothers had used PCS or AAC devices on a regular basis.

Procedure

Four families attended five individual sessions at Lenox Baker Children's Hospital in Durham, North Carolina, and participated in 4-monthlong intervention phases at home. During each 2hr session, parents were introduced to new equipment and procedures while the girls engaged in play-based literacy and communication sessions with the researchers. Between each session, the mothers and girls participated in four phases of storybook readings at home. Using a method that allowed comparison across dyads (Barlow & Hersen, 1984), each family videotaped two weekly mother-daughter readings across all four phases. Families mailed in the videotapes weekly using preaddressed, stamped envelopes. The entire study lasted for 4 months.

Session I. After the overall goals of the study were explained, parents were provided VHS-C video cameras, tripods, videotapes, and preaddressed, stamped envelopes. Parents were given instructions about the operation of the video camera and its use in videotaping storybook readings. Specifically, we asked families to videotape at approximately a 45° angle in front of the mother and daughter so that their eyes would not be hidden behind the books. We also asked them to videotape the girls' entire bodies so that their nonverbal behavior could be observed. Parents were also asked to select two storybooks that they believed would be of interest to their daughters from a display of more than 30 children's storybooks. One book was to be a familiar book that they recalled being read to their child either at home or at school, and the other an unfamiliar book that they could not recall being read to their daughter.

Our main goal during this initial session was to familiarize ourselves with the girls' modes of communication. We also wanted to gather baseline information regarding their interests, communication, use of simple technologies, and emergent literacy understandings. The videotapes of Session I were reviewed repeatedly by the research team to learn as much as possible about these areas and our interactions with the girls.

Phase I (Baseline). The purpose of Phase I was to record the typical ways in which mothers and their daughters interacted during storybook readings at home. Mothers were asked to read the unfamiliar book only twice a week and to video-tape each occasion. They were allowed to read the familiar book as often as they and their daughter liked; however, they were only asked to videotape the interactions on the 2 days that they recorded the unfamiliar storybook reading.

Session II. During this session, hand splints were custom-made by a registered occupational

therapist (OTR) during play-based interactions with the girls. Each girl wore the custom-made splint on her nondominant hand for 20 min so that pressure points and other indicators of incorrect fit could be assessed.

As in all sessions, parents chose a new unfamiliar and a familiar storybook for their readings at home. (The familiar book of this phase might have been an unfamiliar book from Phase I; however, mothers almost always chose new familiar books.) In all phases, the books provided by the research team were carefully selected to reflect the range of topics and book types found in typical early childhood settings. Many of the books had repeated lines, and several were based on familiar children's songs. None included more than three or four lines of text on a single page, and all had photos or illustrations throughout the book. The titles of these books were documented so that we could create appropriate communication symbols for use in Phase III of the study.

Phase II (Hand Splinting). This phase investigated the effects of a resting hand splint, worn on the girls' nondominant hand, for communication intervention and participation during storybook reading. Parents were directed to have their daughter wear the splint during all storybook readings and were encouraged to explore its usefulness in other environments. Amy and Baylee, who already wore elbow splints, continued to wear them with the hand splint. The use of the splints and their rationale (i.e., that they might increase the girls' ability to use the dominant hand for pointing, grasping, and manipulating) were explained to parents. No other guidance or suggestions were provided regarding interactions or reading strategies. The directions regarding storybook reading remained the same as in Phase I.

Session III. During this session, each family was given (a) PCS (Mayer-Johnson Company) to accompany the books they selected, (b) a singlemessage AAC device (AbleNet, Inc.), (c) a fourmessage AAC device (Enabling Devices/Toys for Special Children), and (d) a variety of stands made from polyvinyl chloride (PVC) pipe to be used for mounting the AAC devices and PCS.

The PCS represented repeated lines and key vocabulary from the books that were available for selection. For example, PCS for the book *Brown Bear, Brown Bear, What Do You See*? (Martin, 1992) represented the main characters and the repeated line, "What do you see?" All PCS were laminated to increase durability with velcro attached to the back of each. Velcro was also placed on pages in the book so that the PCS could be used during readings. The families also received a nine-location communication board with the same PCS so mothers could model pointing to the PCS as a form of communication.

The parents were given directions regarding the mechanical operation of the AAC devices (e.g., how to record a message). During this phase, however, we intentionally provided no guidance regarding the use of the devices and how they could support communication and interaction.

The PVC pipe was purchased from a local hardware store, cut using standard PVC cutters, and connected with PVC joints. Some joints were glued whereas others were carefully labeled so that the stands could be disassembled for transport and later reassembled with ease. Parents received two stands: (1) an eyepointing frame (24 inches on each side) to be used to display PCS during reading and (2) a stand that placed the single-message AAC device at a 45° angle. For Baylee, the single message AAC device was mounted at a 90° angle approximately 2½ feet off the floor so that she could activate the device with her head while she sat cross-legged on the floor.

Phase III (Assistive Devices). The purpose of this phase was to study the impact of a variety of assistive technologies on the storybook readings and communicative interactions when no guidance beyond operational use was provided. Our goal was to simulate the experience of many parents who find technologies at conferences or in catalogues and decide to explore independently the utility for their own children. Parents were instructed to use the technologies as best they could and to videotape their attempts twice a week as they read the familiar and unfamiliar books with their children. As in previous phases, the parents selected new familiar and unfamiliar books and mailed the videotapes weekly in the self-addressed, stamped envelopes provided.

Session IV. During this session, and after a careful review of the videotapes from Phase III, we provided training to each of the mothers regarding the effective use of the technologies pro-

vided in Phase III. The specific strategies did not differ across parents, but parents were taught to apply the strategies in individual ways. For example, the research team viewed Phase III videotapes to calculate estimated response times for each girl. In Session IV, all parents were taught to wait for a response, but each mother was given individualized instructions on how long to wait for her daughter. Each mother practiced the strategies in the clinic. Total training time for modeling, practicing, and asking questions was approximately 90-120 min for each family. During this session, mothers chose new familiar and unfamiliar books for Phase IV. The general intervention strategies introduced to the mothers were:

Attribute meaning to the girls' attempts to communicate even if their meaning is uncertain. In many cases, the girls were vocalizing and gesturing during the storybook interactions, but their meaning was unclear. Parents were taught to acknowledge the attempts and give them meaning through an oral response. For example, during the reading of *The Very Quiet Cricket* (Carle, 1990), one girl shrieked and looked at her mother when she turned the page to the picture of the cicada. The mother was taught to reply with expressions like, "Oh, you like that beautiful picture of the cicada, don't you? I wonder if we could find a cicada in the field near our house?"

Instead of saying, "Hit your switch," when it was their daughter's turn to communicate, mothers were encouraged to ask questions like, "Do you think Spot is under the bed?"

Prompt the use of communication devices or symbols through natural questions and comments rather than commands. Mothers often guided their daughters to use the devices and symbols by telling them to "hit your switch" or "look at the ______." We instructed parents to think of the AAC devices and PCS as their child's voice. We encouraged them to ask questions that their child could answer with available symbols and mes-

sages. For example, in the reading of the book

Where's Spot? (Hill, 1980), many of the mothers

prerecorded the line, "No," into the AAC device. Instead of saying, "Hit your switch," when it was their daughter's turn to communicate, mothers were encouraged to ask questions like, "Do you think Spot is under the bed?" The child could use the AAC device to respond, "No." Mothers were also taught to demonstrate use of the symbols and devices themselves while they read and interacted with their daughters.

Provide sufficient wait time and support after asking a question. When the girls did not respond quickly and independently, mothers tended to provide immediate hand-over-hand support in the first three phases. Instead, we reviewed videotapes to determine each child's typical response time, and we taught the mothers to wait the 8 to 30 s their child required before repeating the questions. If the child failed to respond appropriately to this second opportunity, mothers were taught to provide informative feedback. For example, when one child incorrectly selected "waawaa" as the sound that the bus horn makes in the book The Wheels on the Bus (Raffi, 1998), her mother was taught to respond, "Horns go 'beepbeep'; babies go 'waa-waa,'" and to model the correct response using the child's PCS and voice-output devices. Hand-over-hand assistance was not provided until each of the three previous steps were completed.

Consistently ask questions and make comments that maximize the use of available symbols and voice-output messages. Mothers were asked to survey the stories before reading to their daughters and to select the vocabulary that occurred with the highest frequency for the voice-output devices.

Phase IV (Parent Training). This phase evaluated the effects of parent training on the storybook interactions. In short, we wanted to see what improvements, if any, could be made from Phase III by providing minimal parental instruction described previously. Parents continued to videotape the storybook readings twice a week and mailed the tapes to the research team.

Coding of Videotapes

We coded 195 mother-child storybook interactions and nearly 20 hr of videotape for both parent and child variables across the four phases. We adapted our coding mechanism from an existing storybook interaction protocol that has been used in research on children with cerebral palsy (Light, Binger, & Kelford Smith, 1994).

Child and parent variables were each divided into communication modes, communication acts, and reading behaviors. Communication modes described ways in which the child might convey a message (e.g., vocalizing, eyepointing to symbols). Communication acts described why the child communicated (e.g., to respond yes/no, to label or comment, etc.). Reading behaviors were divided into turning pages and visually attending to either the book or the mother. The unit of analysis was the single utterance. Repetitions of utterances were coded as separate utterances (under our repetition categories), and all codes were based on utterances external to the storybook text (e.g., we did not code instances in which the mothers read the text with dramatic expression.) We focused solely on the communication between the parent and the child during each storybook reading event. A complete list of these codes and definitions can be found at http:// www.med.unc.edu/ahs/clds/resources.html and is available, by request, from the author.

Our interobserver agreement was calculated by dividing the number of agreements by the summed total of agreements, disagreements, and omissions. One of us coded all of the videotapes, and another randomly coded 20% of the storybook reading sessions, sampling from each phase (range = 16%-24%) and each child (range = 19%-21%). An overall percentage agreement was calculated for each phase, child, and parent using the above formula. Reliability coefficients were .91 or better. Disagreements and omissions were resolved in discussion among the three authors.

DATA ANALYSES

We timed the length of each storybook reading, beginning when the mother first opened the book or first talked about the book and ending when the mother closed the book or stopped talking about the book. Because the amount of time spent reading these books varied widely by family (see Table 1), we calculated the frequencies for each of the variables by dividing the number of observations of particular behaviors by the length of the storybook reading in minutes. This established a common metric for comparing the parent-child dyads and individual storybook readings. We plotted these frequencies by phase and looked for trends. Based on the results of analysis previously reported (Koppenhaver, Erickson, & Skotko, 2001), as well as subsequent analysis of the mothers' data, all data regarding the familiar and unfamiliar conditions have been collapsed by phase because no significant differences were identified across these conditions.

For each dyad, we calculated the correlations between the following per-minute frequencies: (a) child versus child, (b) parent versus parent, and (c) child versus parent. Variables were matched on a one-to-one basis by individual storybook reading. We report the r values and highlight those correlations that are significant at the 0.05, 0.01, and 0.001 p values. During the exploratory analysis, we discovered that across several parent and child variables, our repetition codes and nonrepetition codes were highly collinear. These variables were collapsed into single codes: (a) attention (AT), (b) labeling (LAB), (c) describing (DES), (d) relating a scene to the child's life (REL), and (e) directing the child to do something (DIR). Likewise, the codes differentiating girls' lengths of attention were highly collinear. These variables were collapsed into single codes: (a) attention to book (ATB) and (b) attention to parent (ATP). Finally, for our correlation analysis, we were concerned solely with the number of times a parent or child pointed or eyegazed to a book or PCS, regardless of whether or not the action was deemed successful or unsuccessful. Consequently, the "successful" and "unsuccessful" variables were collapsed to single variables: (a) pointing to symbols (PS) and (b) pointing in books (PB).

We also generated two multiple regressions for each dyad to determine which parent variables best predicted a girl's appropriate switch use (SS) and which best predicted a girl's labeling and commenting (LC). In other words, our dependent variables were successful switch use and labeling/commenting, and our independent variables were parent codes: (a) requests for attention (AT), (b) pointing to symbols (PS), (c) pointing in books (PB), (d) labeling (LAB), (e) describing (DES), (f) relating scenes to the child's life (REL), (g) directives (DIR), (h) action in the book (AB), (i) prediction or inference comments

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min (SD) -	I	П	Ш	IV	Tatel
Amy	14 2.92 (1. 46)	16 9.32 (0.85)	8 5.35 (0.99)	11 4.47 (1 .7 4)	49 3.45 (1.18)
Baylor	11 5.01 (1.60)	7 6.49 (2.74)	6 7.67 (3.75)	10 4.72 (2.73)	5.70 (2.76)
China	19 6,06 (4.05)	23 7.38 (1.99)	7 7.74 (3.98)	19 7.01 (1.89)	68 6.95 (2.89)
Peterie	10 6.09 (2.12)	12 5.95 (2.10)	4 8.06 (2.52)	16 11.05 (2.27)	42 8.11 (5.19)

Tanus I Number and Duration of Storybook Bradings by Phase

Note: The first carry in each box represents the number of storybook interactions between mother and child. The second entry represents the strenge duration of the interaction in minutes, followed by the SD in pureachests.

TABLE B Personality of Secondal Big Mach Uses by Phase

		Pa		
	I	Ш	Ш	N
Amy	0%	096	\$396	58%
Bayler	0%	096	0%	73%
China	096	096	6996	65%
Petraic	75%	096	33%	68%

and questions (PI), (j) emphasizing print or sound concepts (PC), (k) confirming or requesting clarification (CRC), (l) behavior management (B), and (m) assisting the girl with turning of the pages (TPAC). Variables were entered at a probability of 0.05 using a mixed stepwise regression. We report the standardized s and R^2 values from the last step of our regression. An ANOVA was also run on each predictor variable in the multiple regression, and we report the *df*, *F*, and *p* values.

RESULTS

GIRLS

Previously, we have reported the results of our child variables in detail (Koppenhaver, Erickson, & Skotko, 2001). Splinting the nondominant hand, alone, did not have an impact on the child's communication modes, communication acts, or reading behaviors. It was only when PCS and AAC devices were provided in Phases III and IV that the girls were able to communicate with their mothers at a meaningful level more than once per minute. By Phase IV, each girl was successfully using a single-message AAC device at a level greater than chance (see Table 2; range: 58%-72%). The most common use for the AAC device was to label or comment.

Correlation Among Child Variables. We calculated the correlations between child variables for each individual girl to determine which, if any, often occurred together. In all 4 girls, successful switch use (SS) was highly correlated with unsuccessful switch use (SU) and labeling/commenting (LC; p < 0.001). Unsuccessful switch ac-

tivation was correlated with labeling/commenting for all 4 girls (p < 0.01). In other words, the girls' successful labeling, commenting, and switch use was accompanied by an increase in unsuccessful switch use (i.e., using the switch at an inappropriate time in the interaction or reading.) All of the other statistically significant correlations occurred, at most, in two girls. Amy's and Baylee's vocalizations (VO) were correlated with their facial expressions (FE; Amy: *p* < 0.01; Baylee: *p* < 0.001); attention given to their mothers (ATP) was correlated with their successful switch use (SS; Amy: p < 0.01; Baylee: p < 0.01), unsuccessful switch use (SU; Amy: *p* < 0.01; Baylee: *p* < 0.05), and labeling and commenting (LC; Amy: p < 0.01; Baylee: p < 0.01). China's and Petesie's attention given to the book (ATB) was correlated with their vocalizations (VO; China: p < 0.01; Petesie: p < 0.05).

Mothers

Communication Modes. All mothers had increased frequencies of successful, unsuccessful, and assisted pointing to symbols (PSS, PSU, and PSA) in Phases III and IV in comparison to Phases I and II. To determine if the mothers were able to improve their success rate at pointing (i.e., pointing to capture their daughter's attention), we divided successful pointing to symbols (PSS) by the sum of PSS, unsuccessful pointing to symbols (PSU), and assisted pointing to symbols (PSA) for each phase. All four mothers showed an increased percentage of successful pointing to symbols across phases (see Figure 1). During Phase I, no successful pointing occurred for any dyads. By Phase IV, China's mother was able to point to symbols with an 87% success rate, Petesie's mother with 59%, Amy's mother with 19%, and Baylee's mother with 10%.

All mothers had decreased the frequencies of successful, unsuccessful, and assisted pointing in the book (PBS, PBU, and PBA) in Phases III and IV in comparison to Phases I and II. To determine if the success rate had changed (i.e., pointing in a book to capture a child's attention), we divided successful pointing in the book (PBS) by the sum of successful pointing in the book (PBS), unsuccessful pointing in the book (PBU), and assisted pointing in the book (PBA) for each phase. All 4 mothers relatively maintained the same success rate throughout all four phases (see Figure 2). Three out of the 4 mothers had success rates greater than 50% across all four phases (ranges: Amy, 22%-38%; Baylee, 50%-55%; China, 69%-76%; Petesie, 88%-94%). None of the mothers showed any consistent patterns for performing actions from the book (AB), perhaps because the children's physical ability to engage in such actions themselves was so limited.

Communication Acts. When plotted by phase, the mothers changed their usage of some communication acts over time (see Figure 3). From Phase I to III, all of them increased the number of direct commands (DIR) that they gave their daughters. By Phase IV, however, 3 mothers quite dramatically dropped the numbers of direct commands that they used. They seemed to have replaced the direct commands, as instructed by the research team, with prediction or inference comments and questions (PI), demonstrated by the consistent increase in prediction or inference comments and questions for all 4 mothers across phases. Instead of directing the child (e.g., "Hit your switch now."), mothers were asking children to make inferences (e.g., "What do you think will happen now?"). In essence, their unilateral commands had been replaced by partnered dialogue. Petesie's mother, however, maintained high levels of directiveness (DIR) while simultaneously increasing her use of prediction and inference (PI).

All of the mothers also changed their responses to their daughters' communication attempts with increased amounts of confirmation, praise, negation, and requests for clarification (CRC) in two or more of the intervention phases (see Figure 4). In Phase I, the frequency of requests for clarifications per minute ranged from 0.22 to 0.31; by Phase IV, the frequencies had increased to a range of 0.80 to 2.19. The other communication act variables (AT, LAB, DES, REL, PC, B), however, did not reveal consistent patterns for more than 2 mothers across time.

Reading Behaviors. No more than 2 mothers showed a consistent pattern in assisting their daughter in turning the books' pages (TPAC).

Correlation Among Parent Variables. We calculated the correlations among parent variables for each individual mother to determine which, if any, often occurred together. In all 4 mothers, directing the child (DIR) was significantly correlated with a confirmation or request for

FIGURE 1 Parents' Percentage of Successful Pointing to Symbols Increases







FIGURE 3

Frequency of Parent Communication Acts



clarification (CRC; p < 0.001). In other words, as the mothers directed their children more, they also sought more confirmation or clarification regarding their interpretations of their child's actions and intents. For 3 mothers, pointing to symbols (PS) was significantly correlated with pointing in the book (PB; Petesie: p < 0.05; Baylee: p < 0.01; Amy: p < 0.001) as well as prediction or inference (PI; Petesie: p < 0.05; Baylee: p < 0.001; Amy: p < 0.001). In other words, for these mothers, modeling by pointing to pictures or words in the book or to symbols was accompanied by more prediction or inference questions. All other variables were significantly correlated, at most, in 2 mothers. For Petesie's and Amy's mothers, pointing to symbols (PS) was correlated with confirmations or requests for clarification (CRC; Petesie: p < 0.001; Amy: p < 0.01). Also, for Amy's and China's mothers, labeling (LAB) was negatively correlated with confirmations or requests for clarification (CRC; Amy: p < 0.05; China: p < 0.001).

Child and Parent Variables Compared

We calculated the correlations between parent and child variables for each individual dyad to determine which, if any, often occurred together (see Tables 3, 4, 5, and 6). In three dyads, successful switch use (SS) and unsuccessful switch



FIGURE 4 Frequency of Parents' Confirmations or Requests for Clarification

use (SU) were significantly correlated with parent confirmations or requests for clarification (CRC; Petesie, Amy, China: p < 0.001); unsuccessful switch use (SU) was significantly correlated with parents' pointing to symbols (PS; Petesie: p <0.001; Amy: *p* < 0.05; Baylee: *p* < 0.05). In three dyads, child labeling (LC) was significantly correlated with confirmation and requests for clarification (CRC; Petesie, Amy, China: p < 0.001). In two dyads, successful switch use (SS), unsuccessful switch use (SU), and labeling or commenting (LC) were significantly correlated with parents' directing their child's behavior (DIR; Petesie, Amy: p < 0.001). In another two dyads, successful switch use (SS) was correlated with parents' eliciting predictions and inferences (PI; Petesie, Baylee: p < 0.001), and child responses to yes/no questions (YN) were correlated with parental requests for attention (AT; Petesie: p < 0.05; Baylee: p < 0.05; Bayle 0.001). As each parent-child interaction is a unique one, it is also important to consider the correlations of each dyad separately.

Petesie. Petesie's mother's confirmations or requests for clarification (CRC) correlated significantly with five child variables (Table 3): (a) eyepointing to symbols (ES), (b) successful switch use (SS), (c) unsuccessful switch use (SU), (d) labeling/commenting (LC; p < 0.001), and (e) directing the parent (DP; p < 0.05). Mother's prediction or inference questions (PI) correlated significantly with the same five child variables: ES, DP (p < 0.05), SS, SU, and LC (p < 0.001). Parent directing child behavior (DIR) correlated with four of the same child variables: ES (p < 0.05), SS, SU, and LC (p < 0.001).

Additionally, the mixed stepwise multiple regression analysis revealed that successful switch use (SS) could be best predicted by prediction or inference questions (PI), direct commands (DIR), turning pages/assisting child (TPAC), and attention (AT) (SS = 0.31 AT + 0.38 DIR + 0.55 PI -0.41 TPAC, $R^2 = 0.64$). This means that for every one unit increase in the mother's attempt to draw attention (AT), all other variables held constant, Petesie responded with a 0.31 unit increase in successful switch activation, F(0.05; 1, 11) =7.40, p < 0.01. In other words, if Petesie's mother were to call attention to the book (AT) 10 times in one min (and do nothing else), Petesie would be predicted to activate the switch successfully 3.1 times in that same minute. Similarly, if Petesie's mother were to give 10 directives (DIR) in 1 min (and do nothing else), Petesie would be predicted to activate the switch successfully 3.8 times, F

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Verledder	13	8	Q.Z.V	4.T.V	8	2	33	ŝ	λĨ	5	20	22
AT	-0.14	0.02	-0.14	603	1070-	-0.15	-001	-0.21	10.35	-0.18	9970	- 0 .10
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TABB B Correlations Basesons (Brild and Parent Variables for Patric (N = 42) to Turn Page. Prove Variables. AT - Attention P3 - Pointing to Symbolic P6 - Pointing to Back LAB - Labeling DES - Description: REL - Relating to Child's Experiences DIR - Directing Childs AB - Action in Book P1 - Prediction/Inference: PC - PriorStoned Conceptor CRC - Confirming or Requesting Clarification: B -Behavior Management TPAC - Tenning Pages Ambridge Child.

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Exceptional Children

TABLE 8 Convictions 2	Between Child	and Point S	(कांग्रेसिंह कि 1	(i) (N = 49)							
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ı error verse resonant so - opporting to option to - opporting to note ALB - Attention to Martha to Parta VU - Vegilariton PE - Excid Expression, SS = Successful Switch Use; SU = Unaversatial Switch Use; YN = YarMo; LC = Label and/or Connectr; DP = Directing Parta; TU = Unaversatial Arcompt to Ture Pages Press Veriables: AT - Attention PS - Printing to Spatial AP - Printing to Book LAB - Labeling DES - Description, REL - Relating to Culd's Expressions: DB - Directing Culd. AB - Action in Book; PJ - Pediction/Inference; PC - PrintiScand Conserve DES - Description, REL - Relating to Culd's Expressions: DB - Directing Culd. AB - Action in Book; PJ - Pediction/Inference; PC - PrintiScand Conserve CBC - Confirming or Requesting Cald's Educion Management, TPAC - Thering Pages, Astisting Chid. " > < 0.05, " y < 0.01, " p < 0.001.

(0.05; 1, 11) = 13.27, p < 0.001. By extension, for every 10 prediction or inference (PI) questions, there would be a 5.5 increase in successful switch activation, F(0.05; 1, 11) = 28.09, p < 0.001. Conversely, for every 10 additional times her mother attempted to assist Petesie in turning a page each minute (TPAC), Petesie would be expected to activate a switch successfully 4.1 fewer times, F(0.05; 1, 11) = 12.41, p < 0.001.

Mixed stepwise multiple regression analysis also revealed that labeling and commenting (LC) could be best predicted by PS, DIR, AB, and PI (LC = -0.35 PS + 0.53 DIR - 0.31 AB + 0.67 PI, $R^2 = 0.74$). This means that for every one unit increase in the number of times Petesie's mother pointed to symbols, all other variables held constant, Petesie responded with a 0.31 unit decrease in the number of her labels and comments, F(0.05; 1, 11) = 12.76, p < 0.001. In other words, if Petesie's mother pointed to symbols 10 times in 1 min, Petesie would be expected to respond with 3.5 fewer labels and comments. Similarly, if Petesie's mother gave 10 directives in 1 min and did nothing else, Petesie would be predicted to label and/or comment 5.3 times, F(0.05; 1, 11) =30.37, p < 0.001. By extension, 10 actions from the book would predict 3.1 fewer labels and comments, F(0.05; 1, 11) = 13.96, p < 0.001; and 10 prediction or inference questions would predict 6.7 labels and comments, F(0.05; 1, 11) = 60.14, p < 0.001

Baylee. Baylee's mother's elicitation of predictions and inferences (PI) was significantly correlated with five child variables (Table 4): (a) attention to book (ATB; p < 0.05), (b) attention to parent (ATP; p < 0.05), (c) successful switch use (SS), (d) unsuccessful switch use (SU), and (e) labeling/commenting (LC; p < 0.001). The mother's pointing to symbols (PS) was significantly correlated with four of those variables and one other: vocalizations (VO), SU (p < 0.05), ATP (p < 0.01), SS, and LC (p < 0.001).

A mixed stepwise multiple regression analysis revealed that successful switch use (SS) could be best predicted by PS (SS = 0.74 PS, R^2 = 0.53). For every 10 additional times that Baylee's mother pointed to a symbol every minute, all other variables held constant, Baylee would be predicted to activate the switch successfully 7.4 times in that same minute F (0.05; 1, 10) = 38.19, p < 0.001. Another mixed stepwise multiple regression analysis revealed that PS could also predict labeling/commenting (LC = 0.73 PS, R^2 = 0.52). For every 10 times that Baylee's mother points to a symbol, and does nothing else, we would predict that Baylee would label or comment 7.3 times F (0.05; 1, 10) = 36.6, p < 0.001.

Amy. Amy's mother's confirmations or requests for clarification (CRC) was significantly correlated with five child variables (Table 5): (a) directing the parent (DP; p < 0.01), (b) attention to pictures (ATP), (c) successful switch use (SS), (d) unsuccessful switch activation (SU), and (e) labeling and commenting (LC; p < 0.001). The mother's direction of the child's behavior (DIR) was significantly correlated with four child variables: ATP (p < 0.01), SS, SU, and LC (p < 0.001). Pointing in the book (PB) was negatively, yet significantly, correlated with three child variables: SS, SU, and LC (p < 0.01).

A mixed stepwise multiple regression analysis revealed that successful switch use (SS) could be best predicted by directing the parent (DIR) and requests for clarification (CRC) (SS = 0.34DIR + 0.45 CRC, $R^2 = 0.49$). This means that for every 10 times that Amy's mother gave a direction each minute, all other variables held constant, we could anticipate that Amy would activate the switch successfully 3.4 times F(0.05; 1, 10) =6.40, p < 0.01. Also, for every 10 times that Amy's mother provides confirmations or requests for clarification, we would predict that Amy would respond with 4.5 successful switch activations during that same minute F(0.05; 1, 10) =11.43, p < 0.01. Similarly, analysis revealed that labeling/commenting (LC) could be best predicted by direct commands (DIR) and requests for clarification (CRC) (LC = 0.36 DIR + 0.42 CRC, $R^2 = 0.47$). For every 10 times per minute that Amy's mother issued a directive, all other variables held constant, we would predict that Amy would label or comment 3.6 times, F(0.05;1, 10) = 6.76, p < 0.01. For every 10 requests for clarification or offers of feedback, Amy would be predicted to successfully label or comment 4.2 times, F(0.05; 1, 10) = 9.26, p < 0.01.

China. Of the correlations found between parent and child variables for China (Table 6), the mother's confirmations or requests for clarification (CRC) were significantly correlated with four child variables: (a) unsuccessful attempts to turn the pages (TU; p < 0.05), (b) successful switch use (SS), (c) unsuccessful switch use (SU), and (d) labeling/commenting (LC) (p < 0.001). Parent labeling (LAB) was also significantly correlated with three of these child variables and one other: vocalizations (VO), SU (p < 0.01), SS, and LC (p < 0.001).

A mixed stepwise multiple regression analysis revealed that successful switch use could be best predicted by AT, DIR, and CRC (SS = 0.21 AT - 0.42 DIR + 0.65 CRC, $R^2 = 0.36$). For every 10 additional times that China's mother called for attention (AT) each minute, with all other variables held constant, we would predict that China would respond with 2.1 successful switch activations, F(0.05; 1, 11) = 4.27, p < 0.05; 1, 110.04. Similarly, for every 10 times that China's mother gave a direction, China should respond with 4.2 fewer successful switch activations, F(0.05; 1, 11) = 14.82, p < 0.001. Finally, with all other variables held constant, every 10 times that China's mother gave confirmations or requested clarifcation in a minute, China would be expected to respond with 6.5 successful switch activations, F(0.05; 1, 11) = 36.9, p < 0.001.

Another mixed stepwise multiple regression analysis revealed that labeling/commenting could be best predicted by pointing to book, direct commands, and confirming or requesting clarification (LC = -0.19 PB - 0.40 DIR + 0.65 CRC, $R^2 = 0.42$). For every 10 times that China's mother pointed to the book, China would be expected to respond with 1.9 fewer labels and comments, F(0.05; 1, 11) = 4.22, p < 0.05. For every 10 directives, China would be predicted to respond with 4.0 fewer labels and comments, F(0.05; 1, 11) = 15.67, p < 0.001. However, for every 10 confirmations or requests for clarification from her mother, China would be expected to respond with 6.5 additional labels and comments, F(0.05; 1, 11) = 40.45, p < 0.001.

DISCUSSION

Across the four phases, the girls and their mothers developed an increased synergy in their communicative interactions. What seemingly began as What seemingly began as two separate and often misaligned attempts to communicate in Phase I evolved into more of a mutually respected and synchronous dialogue by Phase IV.

two separate and often misaligned attempts to communicate in Phase I evolved into more of a mutually respected and synchronous dialogue by Phase IV.

The correlation analyses suggest that all 4 girls used the single-message AAC device as a primary means to label or comment, which is to be expected given that mothers typically programmed labels or comments into these devices. Successful use of these single-message AAC devices was also associated with its unsuccessful use by all 4 girls, suggesting that, at least initially, increased success is accomplished through an overall increase in the number of attempts, whether successful or not. However, it is important to note that by Phase IV, all girls were using their singlemessage AAC devices successfully at a rate greater than chance (range: 58%-72%).

The mothers showed a change in reading and interaction behaviors across the phases. During Phase I, they typically just read the text verbatim, often with dramatic emphasis, but rarely paused to insert comments or questions about the text to their daughters. By Phase IV, all mothers were going beyond the text by pointing to PCS, asking prediction or inference questions, labeling, describing, and relating the text to the child's life. One significant change involved pointing to PCS (Figure 1). In Phases I and II, PCS were not provided. When they were introduced in Phase III, only 2 mothers were able to use them successfully. By Phase IV, all 4 mothers were successfully modeling the use of PCS and waiting for their daughters to attend to the PCS during the storybook reading. Simultaneously, the mothers maintained their rates of pointing to the pictures and words in the books.

Perhaps most noteworthy was the mothers' change from using directives to asking questions between Phases III and IV (Figure 3). As the single-message AAC devices were made available

during Phase III, the parents' first inclination appeared to be to treat it as an object to be acted on. "Hit your button," was commonly heard throughout Phase III. However, by Phase IV, parents began to see the device as an extension of their daughters' voice, as evidenced by the increased use of such questions as "What do you think will happen next?"

In sum, we observed that the girls engaged in more successful communication attempts across phases, and we further observed that mothers began to adapt their reading strategies over this same period of time.

All mothers also increased their confirmations and requests for clarification across the four phases, providing approbation for successful communication attempts and suggestions for unsuccessful ones. One way that mothers supported their children in producing more successful responses was by modeling the use of PCS by pointing. For example, in three of the dyads, the mothers' prediction or inference questions were associated with pointing to symbols. Often after asking one of these open-ended questions, the mother would point to a symbol to model a possible response. The parents also appeared to link confirmations or requests for clarification to their use of directives (e.g., "Hit your switch" was often followed by "good job") in another attempt to increase the likelihood of a successful response from their child in the future.

In sum, we observed that the girls engaged in more successful communication attempts across phases, and we further observed that mothers began to adapt their reading strategies over this same period of time. We then asked: What specific actions from the mothers were associated with the successful actions of the children? In short, we found that what worked for one mother-daughter pair was not necessarily the same as what worked for another dyad.

For Petesie, her mother's confirmations or requests for clarification, use of directives, and use of prediction or inference questions were significantly associated with Petesie's attempts to eyepoint to a symbol, activate her single-message AAC device, and label. It is important to note, however, that Petesie's mother's use of prediction or inference questions was significantly correlated with her use of more directives (e.g., "What's going to come next, Petesie? Hit your switch to tell Mommy.") Therefore, it appears that the combined, rather than independent, use of these directives and prediction or inference questions was correlated with Petesie's increased success.

For Baylee, her mother's use of prediction or inference questions was associated with Baylee's increased attempts to label, use her AAC device, and attend to the book and her mother. Additionally, the mother's pointing to symbols was associated with Baylee's vocalizations, use of her AAC device, labeling, and attending to her mother. Her mother's use of directives was not significantly associated with any of these actions. These data suggest that Baylee communicated more when her mother asked engaging, thought-provoking questions rather than when she asked for specific responses or was directive in other ways. For this dyad, the PCS seemed to be an engaging focus of the storybook readings.

For China, her mother's use of confirmations and requests for clarification was associated with China's increased labeling, page turning, and use of her AAC device. Additionally, her mother's use of labeling was associated with China's vocalizations, labeling, and use of her AAC device. This suggests that both labeling and confirmations or requests for clarification were effective strategies to engage China in storybook communication.

For Amy, similarly to the other girls, her mother's use of confirmations or requests for clarification was associated with Amy's increased labeling, commenting, use of her AAC device, and attending to her mother. Additionally, her mother's use of directives was associated with Amy's labeling, use of her AAC device, and attending to her mother. Unlike with the other girls, Amy's mother's use of prediction or inference strategies was not significantly associated with any changes for Amy. Such results could indicate that either (a) Amy was still in the learning period where directives were essential for her to participate in the storybook reading, (b) Amy communicates best when being told what to do, or (c) Amy's mother's skills at eliciting predictions or inferences were undeveloped. The mother's attempts to point to the books were negatively associated with Amy's use of her AAC device and labeling, suggesting that Amy did not activate her switch while her mother was pointing.

Overall, the single-message AAC device offered the most opportunity for the girls to engage in active conversation with their mothers. Even though all of the girls were novice users of the device at the onset of our study, all were using it at a rate greater than chance by the end of the study. Many different parent behaviors were associated with an increased use of the device by the girls. These behaviors included an increase in directives (Petesie and Amy), confirmations and requests for clarification (Amy and China), a call for attention (Petesie and China), prediction or inference questions (Petesie), and pointing to symbols (Baylee). Together, the multiple regressions suggest that girls with RS can learn to communicate symbolically via a single-message AAC device and PCS; however, their mothers may need to engage in different strategies to facilitate such learning.

The multiple regression analyses also revealed that mothers needed to engage in different behaviors to elicit their daughters' labeling and commenting. For some mothers (Petesie's and Amy's), directives elicited labels and comments from their daughters, but for China, directives had a negative influence. Similarly, Baylee's mother could elicit labels and comments from Baylee by pointing to PCS. For others, pointing to PCS had no influence (China and Amy) or a negative influence (Petesie).

IMPLICATIONS FOR PRACTICE

Storybook reading provides both content and context for joint attention and interactive communication by mothers and their daughters with RS. The results of this study suggest that girls with RS can learn communication skills when they are provided with appropriate assistive technologies and support from their mothers. Although our study took place in homes, there is every reason to believe that similar results could be achieved in classrooms or clinical settings. Based on the study's results, successful storybook interactions include:

Providing access to basic voice-output communication during storybook readings. All 4 girls successfully used the AAC device by the end of the study. However, their parents were patient and accepting of both their successful and unsuccessful use of it while they were learning. It seems that the girls learned to use the device through use, modeling, and confirmations or requests for clarification. Also, the girls appeared to use the device more successfully when their parents began perceiving the device as an extension of their child's voice, rather than as an object to be acted on.

Exploring splints for the child's nondominant hand. During Phase II of our study, all girls were fitted with a splint on their nondominant hand. Although the splint, alone, did not produce significant changes, when it was coupled with the intervention strategies of Phases III and IV, the hand splint appeared to allow the girls greater ability to use their AAC devices, point to books and symbols, and otherwise participate in ways that their autonomic hand-wringing had previously inhibited.

Using multiple communication strategies. Books are underused for communication support if they are simply read verbatim. Parents and educators should use the storybooks as a starting point to promote communication and interaction. In our study, each girl responded best to different combinations of parental behaviors, so it will be necessary to implement a number of strategies over an extended period of time to evaluate which are the most effective for your student. Some of the strategies that were successful included pointing and questioning. Pointing to words and pictures while reading and then talking about them was supportive, particularly once parents realized that a point is only a point if the child is attending. Parents learned to sustain their pointing attempts until the child's attention was directed to the target. Another successful strategy involved asking prediction or inference questions. Such questions appear to validate the child as a contributor to the dialogue with experience and opinions to share.

Assuming competence in the child with RS! Students with RS, as well as other forms of severe or multiple disabilities, can and should be educated with the expectation that they can learn. Assuming competence provides a framework from which teaching and learning can proceed. When the mothers in our study began attributing meaning to their daughters' vocalizations, eyepointing, and gestures, they had no way to know for certain that their attributions were correct. Nonetheless, they made the meanings clear to their daughters and moved on. Although they had no evidence that their child's attempts were intentional, they assumed intent and used it as the basis for teaching. In the end, their assumptions of competence paid off as our data reveal that their daughters learned and were communicating intentionally through a variety of means by the end of our study.

IMPLICATIONS FOR RESEARCH

The results from this study can also sharpen future research protocols and suggest many topics for future scientific inquiry:

Exploring individual differences among research participants. Each of the girls with RS who participated in our study showed improvement; however, they did so in distinct ways. Applying statistics to only aggregated data would have lost the richness of individual differences in this study. Strategies that worked for one girl may not have worked for another. Therefore, pooling their data together might have canceled such individual improvement. In sum, it is important that future research on girls with RS include both individual and population statistics.

Studying the long-term impact on intervention strategies. The results from this study indicate that girls with RS can and do want to communicate at a deeper level. At the end of this study after intentionally minimal intervention from the research team—parents and girls were using PCS and assistive technology with greater success. One of the limitations to our study, however, was that our analyses stopped at the end of the 4-month intervention. It is important that future research address the long-term impact of such interventions. For example, did the parents continue to use and implement the reading strategies 6 months later? 1 year later? Also, did the girls continue to improve their use of labeling and switch activation? Were the single-message AAC device and other assistive voice-output technologies incorporated into other social situations outside of storybook readings (e.g., during dinner conversations, doing homework, trips to relatives)?

Studying more advanced communication. Our research design was a basic, contextualized communication study that was ecologically tested, to the extent that we identified unrealized potential and sought to enhance it in a natural home environment. At the same time, our study results are limited to this home setting. Future research could build on this model and ask the question: Could a similar design be implemented in other environments like the classroom or clinical setting?

Studying reading behaviors and communication outcomes in older girls with RS. The girls in our study ranged in age from 3.6 to 7 years old at the onset. Although the basic results provide important implications for all age groups, our data are limited to this younger group. It is important that future research explore specific strategies that work best for older girls with RS. Can voice-output assistive technologies, like the single-message AAC device, be used with success when reading age-appropriate magazines and books? Or do older girls with RS require different strategies? Also, are the parent communication strategies used by mothers in our study successful in older populations? Or do mothers need to adapt their own strategies as the girls get older?

Need for intervention research and altered expectations. Lastly, the research field has accepted cognitive assessments as representative and accurate measures for a population that has severely limited physical and communication skills. As a result, research primarily has explored very basic cause-effect understanding or communication of needs and wants. The results of our study indicate that girls with RS are capable of higher level communications in supportive environments. Future studies should assume greater competence in girls with RS and explore how to initiate communication, enhance it, and contextualize it across multiple environments and for multiple purposes.

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