

Storybook-based communication intervention for girls with Rett syndrome and their mothers

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Abstract

Purpose: Storybook reading provides a natural language learning context in which to support early symbolic communication. In this study, we explored the impact of (1) resting hand splints, (2) light tech augmentative communication systems such as voice-output devices and symbols, and (3) very basic parent training on the symbolic communication and labelling behaviours of six girls with Rett syndrome.

Method: Mothers and daughters were videotaped as they read familiar and unfamiliar storybooks in their homes.

Results: Group and individual data collected from the six girls indicated that they became more active and successful participants in the interactions during storybook reading. The girls employed a wider range of communication modes and increased the frequency of their labelling. Familiar storybook reading encouraged greater symbolic communication than unfamiliar storybooks in half the girls.

Conclusion: This study suggests that motivated parents may not require expensive technologies or lengthy training in order to enhance their children's early communication and participation in storybook reading.

Introduction

Studies of communication development document a loss of speech skills during the regression phase of Rett syndrome.¹ Some girls may retain a few single words, simple phrases, or, even more rarely, sentences. More typically, girls with Rett syndrome communicate by using non-symbolic means such as gestures, vocalizations and body positioning.² Severe dyspraxia and severe cognitive disability are the accepted explanations of the girls' failure to regain speech.^{3,4} While some researchers suggest that most girls with Rett syndrome rarely communicate above a pre-intentional level (i.e. caregivers assign meaning to the girls' behaviour and children have no expectation or awareness that caregivers will respond),⁵ recent intervention studies raise questions about the inevitability or immutability of communication stasis. Splinting of the nondominant hand, for example, may result in improved ability to purposefully use their hands.⁶ Other researchers reported on improved communication by children with Rett syndrome when they were taught to use a computer with animated graphics.⁷ These studies suggest that, perhaps, dyspraxia can be effectively managed and that attention and learning of girls with Rett syndrome can be motivated by purposeful communication events.

STORYBOOK READING AND CHILDREN WITH MULTIPLE DISABILITIES

Survey and observational studies suggest that children with severe speech and physical impairments may have few opportunities to participate actively in storybook reading with their parents.^{8–10} Parents tend to control storybook interactions by selecting both the activity and the texts to be read. In addition, parents seldom provide nonspeaking children with access to augmentative communication (AAC) systems needed to communicate during reading activities. Consequently, children only tend to participate in the mechanical aspects of reading (e.g. turning pages), responding to questions or directives by pointing to pictures or answering yes/no.

Research has begun to outline necessary elements of successful storybook-based communication inter-

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ventions for children with multiple disabilities. These elements include parent perceptions of child competence,¹¹ child access to multiple forms of communication,¹² and repeated readings of familiar storybooks.¹³ While children with multiple disabilities may have substantial difficulties in learning to communicate and use print, these intervention studies suggest that the problems are not insurmountable.

AIMS OF THE PRESENT STUDY

The present study was part of a larger investigation of storybook reading in the home as a context for early communication and emergent literacy intervention in girls with Rett syndrome. In the study reported here, we examine the effects of resting hand splints, basic assistive technologies, AAC symbols and parent training on the nature and frequency of children's communication during mother-child storybook reading of familiar and unfamiliar books. We were particularly interested in whether and how the girls would engage in labelling during the storybook reading interactions.

Nondisabled children, as young as 8 months old, engage in a great deal of labelling when jointly looking at picture books with their mothers.¹⁴ Picture storybooks, because they offer little to grasp or manipulate physically, appear to provide a natural opportunity for young children to direct their attention to symbolic communication, to treat the book as an 'object-of-contemplation' rather than a 'thing-of-action'.¹⁵ During this joint activity, mothers of nondisabled children interpret their young children's smiling, reaching, pointing, or vocalizing as the provision of or request for labels and they act upon them. Thus it appears that in the case of very young, nondisabled children, early symbolic communication emerges from repeated participation in a fairly ritualized dialogue rather than from imitation.¹⁶ We wanted to explore whether, through the use the interventions described earlier (i.e. hand splits, basic assistive technologies, AAC symbols, and parent training) we could support comparable dialogues between mothers and their daughters with Rett syndrome.

Methods

PARTICIPANTS

Girls

Six girls with a primary medical diagnosis of Rett syndrome participated in the study. The girls ranged in age from 3_.6–7 years old at the onset of the study, and all

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exhibited severe communication impairment as evidenced by limited to no intelligible speech. All of the girls (Abbey, Amy, Baylee, China, Mary and Petesie) communicated through a variety of nonconventional gestures and vocalizations. All except Abbey, who spoke, looked at people or objects to indicate attention, wants, or needs. Abbey, Amy and Baylee were able to ambulate independently, Petesie and China required physical assistance such as hand-holding and Mary used a manual wheelchair that she could not self-propel. All six girls engaged in various forms of hand-wringing, and three girls also engaged in hand-mouthing behaviours. All the others except China and Mary wore elbow splints for portions of each day. Abbey, Baylee and China would grab desired objects within reach. All six girls had normal hearing and vision and all met the criteria of the American Association on Mental Retardation¹⁷ for mental retardation since they exhibited pervasive needs in all major life domains (e.g. self-care, social skills, communication, home living). Age equivalent scores on the Bayley Scales of Infant Development (2nd ed.) ranged from 5 to 19 months and on the Vineland Adaptive Behaviour Scales from 9 to 17 months. Finally, all six girls were perceived by school personnel as functioning in the range of severe to profound mental retardation.

Mothers

All study participants were Caucasian and reported that they read two or more times a week with their daughters prior to involvement in the present study. They used neither augmentative communication symbols nor devices regularly, but two had used a BigMack switch and picture communication symbols at times in the past.

EXPERIMENTAL DESIGN

A multiple baseline design across behaviours was employed with six parent-child dyads¹⁸ in order to evaluate how resting hand splints, basic AAC and assistive technologies and parent training impacted the participants' labelling and modes of communication. The study consisted of a baseline and three intervention phases described below.

PROCEDURES

Families attended five, individual, monthly assessment and informational sessions at Lenox Baker Children's Hospital in Durham, NC across the four months of the study. During these sessions the first author met with each set of parents privately to explain plans for each study phase, introduce equipment and explain procedures. Simultaneously the second, third and fourth authors worked as a team to conduct play-based communication and emergent literacy assessment activities with each girl individually. Each session lasted approximately two hours.

Phase I (baseline)

The principal goal of phase I was to record the ways in which the mothers typically read and interacted with their daughters during storybook reading. During the initial visit, the overall goals of the study were explained to parents. VHS-C video cameras, tripods, videotapes, and pre-addressed and stamped mailers were provided to each family. Parents were instructed in the operation of the cameras and guided in how best to videotape storybook reading (i.e. to videotape at approximately a 45 degree angle and in front of the mother and daughter, so that eyes were not hidden behind books, and to capture the entire length of the girls, so that nonverbal behaviour could be observed). More than 30 children's storybooks were displayed on a table, and each family selected both a familiar storybook and also an unfamiliar storybook that their daughter had not previously read, but likely would be interested in reading. Families were instructed to read the unfamiliar book only twice a week and to videotape on each occasion. They were instructed that they could read the familiar books as often as they, and their daughter, wished to read it, but only to videotape the reading and interaction on the two days that they recorded the unfamiliar storybook reading. Since in all six families, parents agreed that the mother read more often with the daughter, the research team decided to videotape only mother-daughter readings and interactions.

Simultaneous to this parent session, our research team also attempted to familiarize themselves with each girl's modes of communication. The team videotaped each session as they attempted to gather data about the girls' interests, language comprehension, communication, and emergent literacy understanding. Possible locations for best access to switches were also explored.

Phase II (hand splinting)

The goal of this phase was to investigate the effects of a resting hand splint on the participants' non-dominant

hand. These hand splints were custom-made by the sixth author, a registered occupational therapist (OTR), during the families' visit. Parents were asked to identify their daughter's dominant hand and this information was confirmed. In three cases, the parents were unsure and a decision was made through careful observation of play-based interactions with the subjects. Puppets, bubbles, baby dolls and musical instruments were used to entice the subjects to reach out.

Once hand dominance was established, and the splints made, each girl then wore the splint for 20 minutes in the clinic so that pressure points and other indicators of incorrect fit could be assessed. During this time, the research team members continued to interact with the subjects in play and storybook reading. Parents were directed to have their daughter wear the splint during storybook reading, and encouraged to explore its usefulness in other environments. The research team also conducted preliminary investigations of the participants' use of the light technology devices that were to be introduced in the third phase. Accessibility issues, like determining appropriate positions for switches and books, were explored. As in each phase, the parents chose an unfamiliar and a familiar storybook for reading at home. In phases II-IV, the books had a repeated line throughout the book. The titles of the books were documented and appropriate communication symbols were created later for use in the next phase of the study.

Phase III (assistive devices)

The purpose of this phase was to study the impact of a variety of assistive technologies on the storybook reading and communicative interactions. A similar range of technologies and environmental adaptations were introduced to each family, including laminated books and BigMack switches,19 but the positioning of those technologies, specific features of some of the technologies, and environmental adaptations differed by child. Parents were introduced to the operation of the technologies but not provided guidance in their application during communication events. In keeping with a minimalist intervention structure, we were attempting to simulate the experience of many parents who find particular technologies at conferences or in catalogues and explore applications on their own. During this phase, each family was given: (1) a set of Picture Communication Symbols;²⁰ (2) a single-message Big-Mack; (3) a multi-message Four In-Line Cheap Talk;²¹ and (4) a variety of stands made from PVC pipe. The set of Picture Communication Symbols represented the repeated line and key vocabulary of a book they had read

in phase II. For example, symbols from the book *Brown Bear*, *Brown Bear*, *What Do You See*?²² represented the main characters and the repeated line 'what do you see?'. All of the symbols were laminated to increase durability and velcro attached to the back. Corresponding velcro was placed on each page to enable use of the symbols for interaction during reading. The families also received a single, 3-by-3 location communication board with core vocabulary symbols. Mothers could use these displays to model pointing to pictures as a form of communication.

The BigMack, a single-message communication device, provided a means for children to speak a repeated line from the story. A communication symbol could be attached to the BigMack and the corresponding message recorded. The Four In-Line Cheap Talk allowed four picture symbols to be attached and four corresponding messages to be recorded. Children activated this device by touching the switch surface with the appropriate symbols.

In addition to the communication symbols and devices, the parents received a variety of stands made from PVC pipe. An eye-gaze frame was designed to be placed in front of the child. Even for Abbey, who reached for the symbols with her hands rather than pointing with her eyes, the eye-gaze frame provided a place to display the symbols during the readings. All of the families also received a stand on which the BigMack was mounted at a 45 degree angle. For Baylee, the mount held the BigMack at a 90 degree angle about $2\frac{1}{2}$ feet off the floor to facilitate activating the switch with a head movement. Mary, who used a wheelchair, also received a book stand made out of PVC pipe. The book stand resembled a music stand, but had a tripod base that made it more stable when Mary reached out to turn the pages in the book.

Phase IV (parent training)

The goal of this phase was to evaluate the effects of parent training on the nature of the interactions and communication during storybook reading. During the parent session, training was provided individually to each mother on use of the technologies provided in phase III. Careful review of videotapes submitted by parents during the previous phase guided us in developing the guidelines. When families came to the clinic for their fourth monthly visit, strategies were explained to mothers and modelled with the children. Each mother then practiced the strategies as the research team provided additional feedback and guidance. Total training time for modelling, practicing and asking questions was less than two hours for each family. The intervention strategies included :

- (1) Attribute meaning to your child's attempts to communicate even if the 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. For example, one girl shrieked and looked at her mother when she turned the page to the picture of the cicada in the book *The Very Quiet Cricket*. 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.'
- (2) 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 symbols as their child's voice and prompted them to ask questions that the child could answer with available symbols and voice output messages. Instead of telling a child to hit her switch when she missed a communication turn, parents were encouraged to ask, 'Do you think Spot is under the bed?' Then the child could use the BigMack to provide the repeated response, 'No'. Parents were also taught to demonstrate use of the symbols and devices throughout the storybook readings and interactions.
- (3) Provide sufficient wait time and a hierarchy of support after asking a question. When the girls did not respond quickly and independently, mothers tended to immediately provide hand-over-hand support. Mothers were taught instead to wait 10-30 seconds, depending on the child, before repeating a question. After the child failed to respond a second time, mothers were taught to provide informative feedback. When one child incorrectly selected waa-waa as the sound a horn makes, the mother was taught to respond, 'Horns go beepbeep; babies go waa-waa,' and to model the correct response using the child's symbols and device. If the child did not respond after the question was repeated a second time, mothers could provide the child hand-over-hand assistance.
- (4) Consistently ask questions and make comments that maximize use of available symbols and voice output messages as appropriate communication turns.



Figure 1 Average frequencies and ranges of children's successful symbolic communication during reading of familiar storybooks.

Mothers asked to survey the stories before reading and select the vocabulary for voice output that occurred with high frequency.

MEASURES AND DATA ANALYSES

The data reported here result from analysis of one randomly sampled familiar and unfamiliar storybook from each of the four phases. To analyse the videotaped interactions, we adapted an existing storybook interaction protocol used in research with children who have cerebral palsy.23 Children's participation in the storybook interactions was coded by communication mode and communication act. Communication mode included vocalizations; pointing with eyes, fingers, or objects; facial expressions; actions on books (e.g. lifting flaps, pretending to do something based on story content or illustrations such as sniffing a flower); and activation of a voice-output message device. Communication mode was coded only if the child had acted independently, not if the parent provided guidance or hand-over-hand assistance. The only communication act coded for in the present study is labelling, which included labelling pictures by any mode, making comments, or responding to wh- questions.

Interobserver agreement was calculated as follows: number of agreements divided by number of agreements plus disagreements and omissions. The fifth author coded all of the videotapes, and the first author coded one randomly selected familiar and one unfamiliar storybook reading for each child. An overall percentage agreement was calculated for each phase and for each child using the above formula. Reliability coefficients were 0.91 or better. Disagreements and omissions were resolved in consultation between the two coders.

Frequencies of communication mode and labelling per minute were calculated for each child, as well as group means. Following Light's²⁴ recommendations for AAC research, we analysed results both at a molar level, examining overall group performance, and at a molecular level, examining individual case results.

Results

SYMBOLIC COMMUNICATION

With the exception of one girl in phase II of unfamiliar storybook reading, every child attempted to communicate with parents during each study phase for both familiar and unfamiliar books (range = 0.21-10.24attempts/minute). However, only when communication symbols, devices and training were introduced in phases III and IV did successful symbolic communication (i.e. pointing to AAC symbols or using voice output devices at appropriate times that were recognized and acknowledged by mothers) occur at an average rate of more than once per minute for five of six girls (see figures 1 and 2). Abbey, who began the study with the widest available

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Figure 2 Average frequencies and ranges of children's successful symbolic communication during reading of unfamiliar storybooks.

 Table 1 Highest frequencies of individual children's successful symbolic communication in AAC intervention phases with familiar and unfamiliar storybooks

Child	Storybook	
	Familiar	Unfamiliar
Abbey	3 10	4 82
Amy	2 69	1 36
Baylee	0 82	1 01
China	1 32	2 59
Mary	2,33	1 21
Petesie	1 01	0 73

communication repertoire, was able to increase her symbolic communication success rate in phase II to 2 15 attempts per minute with the aid of the splint. Three other girls engaged in successful symbolic communication in phase II: Petesie three times and China 4 times, and Abbey. No girl, except Abbey, engaged in more than one successful symbolic communication act in phase I (see table 1). Every girl achieved a rate of successful symbolic communication greater than once a minute during either familiar or unfamiliar storybook reading in phase III or IV. Each girl's highest rate of successful symbolic communication in either phase III or IV with both familiar and unfamiliar storybooks is found in table 1. Three girls engaged in successful symbolic communication more than once a minute both in familiar and also in unfamiliar storybook reading in phase IV. Individual differences are found in table 2.

LABELS AND COMMENTS

Across familiar and unfamiliar storybooks, all of the girls produced their highest rates of labelling and commenting in phase III or phase IV with both familiar

Table 2Frequencies of children's successful symbolic communicationacts per phase with familiar and unfamiliar storybooks

	Phase			
Girl	1	2	3	4
Abbey				
Familiar	0.00	2,15	3,10	0.41
Unfamiliar	0.87	0.00	4 82	1 11
Amy				
Familiar	0.41	0.00	2,69	0.22
Unfamiliar	0.00	0.00	0 59	1 36
Baylee				
Familiar	0.00	0.00	0.26	0.82
Unfamiliar	0.00	0.00	1 01	0 78
China				
Familiar	0.00	0.34	1,17	1,32
Unfamiliar	0 00	0 14	0 28	2 59
Mary				
Familiar	0.00	0.00	2,33	1 13
Unfamiliar	0 30	0 00	0 25	1 21
Petesie				
Familiar	0.00	0.31	0.64	1 01
Unfamiliar	0 44	0 27	0 54	0 73
Mean				
Familiar	0.04	0.68	1,56	1,33
Unfamiliar	0.28	0.07	1 55	1_19

	Phase				
Girl	1	2	3	4	
Abbey					
Familiar	0.74	1,64	1,83	2,53	
Unfamiliar	0.35	0.29	2 25	0 79	
Amy		-			
Familiar	0.00	0.00	2,69	0.22	
Unfamiliar	0 00	0 00	0 59	0 68	
Baylee	•	•	•	•	
Familiar	0.00	0.00	0.00	0.82	
Unfamiliar	0.00	0,00	0.00	0 78	
China		-			
Familiar	0.00	0.34	0.35	1,32	
Unfamiliar	0 00	0.14	0 14	2,59	
Mary					
Familiar	0.37	0.24	2,33	0.94	
Unfamiliar	0 30	0,00	0 76	0.26	
Petesie					
Familiar	0.00	0.00	0.64	0,91	
Unfamiliar	0 00	0,00	0 54	0.00	
Mean	-	-	-	•	
Familiar	0.18	0.53	0,98	1,26	
Unfamiliar	012	011	0 87	0 65	

 Table 3
 Frequencies of children's labels and comments per phase with familiar and unfamiliar storybooks

and unfamiliar books (see table 3). Group results are reported in figures 3 and 4 below. Four girls (Amy, Baylee, China and Petesie) had baseline rates of no (0 0 labels/minute) labels or comments during both familiar and unfamiliar storybook reading. These girls engaged in continual hand-wringing and hand-mouthing throughout the storybook readings. The four girls (Abbey, Baylee, China and Petesie) demonstrated their highest frequency of labelling in phase IV (i.e. symbols and technologies with training in five strategies) with familiar storybooks (range = 0 82–2 53 labels/minute). Every girl provided labels and comments during phase IV familiar storybook reading (range 0.22–2.53 labels/ minute), the only study condition in which this occurred.

The highest combined rates of labelling across phase III and phase IV (1.65 labels/minute and 2.12 labels/ minute) were achieved during familiar storybook reading by Abbey and Mary, who were able to learn both to point to symbols on the eye-gaze frame and to use the BigMack switch. Baylee only communicated labels and comments in phase IV (0.82/minute during familiar storybook reading, 0.78/min with unfamiliar).

Discussion

Storybook reading at home provided both the content and a structure for joint attention and interactive communication by mothers and daughters in this study. Substantial increases in the frequency of symbolic communication and labelling/commenting were observed in all six participants without highly structured or long-term interventions (i.e. one month for each phase). Symbolic communication and labelling/commenting are addressed separately below.

SYMBOLIC COMMUNICATION

Prior to intervention, the girls relied primarily on nonconventional and nonsymbolic modes of communication such as vocalizations and gestures. Except for Abbey, who had a wide range of preexisting communication modes, phase II results suggest that interrupting stereotypic hand movements with resting hand splints did not dramatically increase the girls' ability to communicate symbolically. Symbolic communication, instead, seemed to increase more as a



Figure 3 Average frequencies and ranges of children's labels and comments during reading of familiar storybooks.

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Figure 4 Average frequencies and ranges of children's labels and comments during reading of unfamiliar storybooks.

function of at least two factors: (1) introduction of communication technologies; and (2) increasing mothers' awareness of and ability to acknowledge the many communication modes used by their daughters. As mothers became more aware of the existence and functions of these modes of communication across intervention phases, especially in phases III and IV, they increasingly modelled alternative modes of communication such as pointing to illustrations or communication symbols as they also spoke. Their daughters responded by demonstrating substantial increases in their use of both nonsymbolic and symbolic communication. Given access to AAC symbols and devices in phases III and IV, each girl produced higher rates of symbolic communication than she had in baseline or with resting hand splints. For some girls and their mothers, access to these forms of support was sufficient (i.e. phase III). For others, basic instruction resulted in an additional increase in symbolic communication. Such increases in understanding and using pictures as symbolic representations are consistent with the understandings that young nondisabled children develop during parent-child storybook reading,25 although their focus is on illustrations only, not AAC symbols.

What is inconsistent with the literature on young, nondisabled children is that half of the girls engaged in their highest rates of symbolic communication in phase III or IV during familiar storybook readings and half during unfamiliar storybook readings. Nondisabled children are described as taking increasingly more active and interactive roles as storybooks become increasingly familiar (i.e. are read and reread). Light and her colleagues reported in their study also that young children with cerebral palsy failed to take a more active role consistently in familiar versus unfamiliar storybook reading. It is possible, as Light and her colleagues suggest, that this is due simply to the low frequency of participants' communications relative to nondisabled children. It may also be, however, that the parentcontrolled nature of storybook reading interactions when AAC systems are included contributes to this inconsistent result. The present study did not separate child initiations and responses, but informal analysis suggests that participants almost solely responded to parent questions or leading comments. Parents are less likely to be interested in interacting during repeated readings of a young children's storybook when they have understood a text fully on initial reading. Unless the child initiates interaction, as speaking children do, communication opportunities are reduced as parents read rather than interact. It may also be the case that available symbols did not represent the girls' interests in communicating about particular stories and, therefore, did not encourage symbolic communication despite their availability. These are issues to be explored in future research.

LABELS AND COMMENTS

Five of the six girls achieved their highest rates of labelling during the reading of familiar books in either phase III or IV. However, China, the youngest participant, provided nearly twice as many labels (2 59/minute vs 1 32/minute) when her mother read an unfamiliar book. Baseline rates of labelling and commenting in phase I by the girls in this study are substantially lower than those reported in a descriptive study of similar-aged children with cerebral palsy, in which the group mean was 0.94 labels/minute with familiar storybooks and 1.34 with unfamiliar.²⁶ The rates for the girls in phases III and IV, with AAC and training interventions, exceed these averages in familiar storybook reading but remain lower with unfamiliar storybooks. Continued AAC interventions in girls with Rett syndrome must explore ways to maximize opportunities to communicate.

Increases in the girls' labelling and commenting appear to be due to the same factors that influenced their increased symbolic communication: access to communication technologies and increases in parents' and children's use of multimodal communication. In baseline, the only means by which children could choose to label were pointing to illustrations or real objects in the immediate environment, both difficult tasks given mothers' relative lack of awareness of their nonconventional communication modes, the girls' dyspraxia, and their inability to interrupt stereotypic hand movements. Hand splints enabled some of the children to choose to label by pointing, but only when picture symbols were made available, and, in some cases, their use modelled.

The means by which individual girls increased their labelling and commenting varied widely. China consistently used the BigMack switch to complete the repeated line in stories that her mother read. Amy, likewise, used the BigMack switch successfully by hand and occasionally eyepointed to communication symbols or illustrations. Baylee eyepointed to picture symbols on an eyegaze frame and accessed the BigMack switch by pressing it with her cheek. Abbey eyepointed, pointed with her hand by touching or grasping, and spoke with words. Petesie seldom used the communication symbols but regularly pointed to pictures in the book as well as accessing the BigMack switch with one or both hands. Mary, the most severely physically impaired of the six girls, eyepointed to communication symbols and accessed the BigMack switch by hand when her nondominant hand was anchored to her lap tray.

Mary provided, perhaps, the richest example of the power of AAC systems for interaction. Her mother had just finished reading a book entitled *Are You My Mommy*? Mary then appropriately eyegazed to both the picture of the hen to appropriately label the baby chick's mommy and then to the symbol for *yes* in response to

the baby chick's question. Her mother responded, 'Yes, Mrs Hen is her mommy. Yes!' Mary again looked at yes and then at her mother, who repeated, 'Yes, Mrs Hen is her mommy. Yes!' Mary smiled at her mother, reached over and touched her BigMack to comment, 'No!' In response, her mom countered, 'Yes, she is. Mrs. Hen is her mommy.' Mary again touched her BigMack, 'No!' and her mother, looking puzzled, said more pointedly, 'Yes, she is. Mrs. Hen is the mommy. Yes!' Mary and her mother looked into each other's eyes, and her mother suddenly understood she was being teased. The two of them commented back and forth several more times, 'yes, she is' and 'no,' before both dissolved into laughter.

CLINICAL AND EDUCATIONAL IMPLICATIONS

Results from the present study suggest that storybook reading interactions between mothers and girls with Rett syndrome can provide a useful context for language and communication learning if supports are made available to participants. This study suggests that these supports include interventions similar to those that have been used with other populations of children with multiple disabilities.27 Mothers in this study had no specialized coursework in AAC, yet were able to help their daughters communicate in new and varied ways. In addition, they did so in the context of their daily lives without a great deal of time devoted in creating materials or equipment and with minimal set-up. This study was conducted in the families' homes, where there are the usual competing demands for time and attention. Nonetheless, mothers read 10-15 minutes, on average, no less than twice a week during the course of this study. In the busiest classrooms, this amount of time is available also. A teacher, a classroom aide or volunteer, or peers who can read fluently all could be taught to use the inexpensive and widely-available strategies and technologies employed in this study.

Clinicians and early interventionists should encourage parents of girls with Rett syndrome to read with their children, provide access to AAC symbols, and train parents in basic strategies such as seeking and attributing meaning to nonconventional communication attempts, providing sufficient wait time, and identifying and targeting higher frequency story vocabulary and concepts for AAC symbol and voice-output message creation. Two aspects of the interaction strategies taught in this study were more difficult than the others for parents to implement. The first was providing a hierarchy of supports to encourage and enable independent child communication. Second, in modelling AAC symbol and device use, mothers often did not point or wait long enough for their daughters to observe the model.

RESEARCH IMPLICATIONS

Results of the present study suggest that interventions need not necessarily be highly complex or overly prescriptive to benefit early symbolic communication of girls with Rett syndrome. In fact, interventions cannot be overly complex or prescriptive if they are to maintain lasting utility beyond the duration of an intervention study. The results of the current study provide a rationale for the design and study of additional family-focused interventions. It is important in future research to explore the supports required for communication development in other naturalistic contexts in which parents and girls with Rett syndrome typically find themselves (e.g. play situations or clinic waiting rooms). The critical issue for families has less to do with optimum environments or strategies than identifying a range of useful strategies to enrich environments already present in the family's life.

Research must begin to address how to move beyond basic communication of labels, wants, and needs. It is apparent from results of the current study and others that it is possible to initiate early labelling and symbolic communication, requests for preferred foods²⁸ and requests for preferred objects.²⁹ It is important to explore strategies and materials needed to support the communication of more complex thoughts and emotions represented by the combination of two or more symbols. In this process, issues of increasing vocabulary access must be more carefully explored. A great deal of research in AAC has focused on aspects of various symbols and symbol systems that make them more easily understood, learned, or used by children. The present study suggests that researchers also must attend more carefully to what aspects of experience and instruction may increase children's attention, engagement, and active participation in interactive experiences leading to symbol learning and use.

In further storybook studies, it is important to explore the reasons for individually different outcomes with familiar and unfamiliar storybooks. No child can progress far on an intellectual diet of only familiar books. It is important to begin to explore what strategies, beyond sheer repetition, can be employed to make unfamiliar books more familiar for those children who communicate more frequently and successfully in such books. It is important to explore what text characteristics, technologies, and parent behaviours lead to increased participation, communication, and independence in children.

All six girls in this study demonstrated an ability to learn and to communicate symbolically when they and their mothers received fairly basic supportive technologies and strategies. It is incumbent upon researchers to identify and refine additional supports. It is incumbent upon clinicians and early interventionists to inform themselves about basic AAC and emergent literacy fundamentals and to share that information with parents of their clients and students.

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