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The Effects of a Parent-Child Communication Activity
on the Worries of Siblings of Children with Autism

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Abstract

This study was designed to obtain objective results about the effects of two different parent-child activities on the siblings of children with autism. Participants were eighteen 6-13 year-old siblings of children with autism and their parents. One group of parent-child pairs completed a workbook focused on autism-specific worries, while another group of parent-child pairs played board games together. The children in each group completed a questionnaire about their autism-related worries at the end of the activity. Results demonstrated that the workbook was useful in making parents more aware of specific worries that their children have as shown by a strong correlation between child report of worries and parent report of child's worries.

The Effects of a Parent-Child Communication Activity on the Worries of Siblings of Children with Autism

Autism is an early onset pervasive developmental disorder (PDD) that is characterized by social deficits, communication abnormalities, and stereotyped repetitive behaviors (Szatmari, 2000). Autism is considered a spectrum disorder, a term that has two implications. First, autism symptoms vary widely from mild to severe, with the majority of children falling close to the midpoint (Powers, 2000). Second, the spectrum includes several overlapping specific diagnoses, including autistic disorder, Asperger's Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified, PDD-NOS, (all technically referred to as the Pervasive Developmental Disorders). Recent studies suggest that as many as 1:500 children qualify for an autism spectrum diagnosis. There are no cultural, social, or economic class differences in the occurrence of autism, but there are many more boys diagnosed than girls with a male to female ratio of 4:1 (Powers, 2000). Due to the many disabilities inherent with autism, having a family member with autism creates many challenges for parents and siblings.

A number of studies have been conducted on siblings of and families with children with disabilities such as mental retardation, learning disabilities and autism (Bagenholm & Gillberg, 1991; McHale, Sloan, & Simeonsson, 1986). Few of these studies are specific to families that have a child with autism and even fewer are specific to typical siblings in these families. The literature that does exist on siblings of children with autism provides conflicting results. One study found that siblings of children with autism tended to have more internalizing and externalizing behavioral problems than siblings of developmentally typical children (Rodrigue, Geffken, & Morgan, 1993). In contrast, another study found that siblings of children with autism did not differ from children with typical siblings (McHale et al., 1986). The variable outcomes

of siblings of children with autism may be explained by the coping mechanisms used to deal with stress that are utilized by the family and child (Lazarus & Folkman, 1984; Summers, Behr, and Turnbull, 1989). The present research attempted to increase autism-specific parent-child communication, which may be a way of making parents more aware of their child's worries so that they can help the children develop more adaptive coping strategies.

To provide background and rationale for the study, the following sections will review the challenges siblings face and the interventions that have been designed to help them. First, typical sibling relationships will be examined to provide a broader understanding of the sibling relationship. Second, the experience of living with a developmentally disabled sibling will be examined. Third, intervention efforts such as behavioral treatment training and support groups will be described as well as the limitations of the research on these topics. Finally, hypotheses for the current study will be presented.

Typical Sibling Relationships

Sibling relationship quality has developmental implications but research in this area has been relatively slow in coming compared to research on marital and parent-child relationships (Cicirelli, 1995). In order to understand how having a sibling with autism might effect development, it is beneficial to examine how sibling relationship quality has been found to effect child development in families without a child with a disability. The potential of the sibling relationship to influence development has been underestimated. Previously, it was assumed that parents exerted the most influence on an individual's behavior and development and while the validity of this assumption is still unknown, it is important to examine other possible areas of influence. With the popularity of family systems theory, in which parent-parent, parent-child,

and sibling relationships are all seen as functioning in an interconnected system of family relationships, new interest in sibling relationships has emerged (Cicirelli, 1995).

Sibling relationships are usually characterized by a combination of warmth and conflict. The immense amount of time that siblings spend together often nurtures warmth, companionship, emotional support and affection (Vandell & Bailey, 1992). Siblings can provide direct aid and services for each other by forming coalitions to deal with parents, providing physical protection, teaching skills, sharing friends or helping with homework (Cicirelli, 1995). In addition, positive sibling interactions have been shown to foster the development of prosocial behaviors such as helping, teaching, and sharing (Stormshak, Bellanti, & Bierman, 1996).

Sibling conflict is also a defining feature of the sibling relationship (Raffaelli, 1992). Much sibling research focuses on sibling conflict and its causes (Garcia, Shaw, Winslow, & Yaggi, 2000). Power issues and personal property disputes were found to be the cause of conflict in over half of sibling disputes (Raffaelli, 1992). Extreme, aggressive sibling conflict may play a role in the development of conduct problems (Garcia et al., 2000). Moderate levels of conflict, however, may provide opportunities for social problem-solving situations where children can learn negotiation skills, affect regulation, and behavioral control (Vespo, 1995; Stormshak et al., 1996).

Although it is not well known how exactly the sibling relationship affects development, there is sufficient evidence to show that the sibling relationship is an important factor in shaping children's outcomes. The experience of living with a sibling with autism may differ in many ways from the experience of living with a developmentally typical sibling, therefore, researchers have recognized the importance of studying these children.

Sibling and Family Experiences of Living with a Child with Autism

Psychological and Behavioral Adjustment of Siblings

The psychological and behavioral adjustment of siblings of children with autism can be affected by numerous variables. Parental marital satisfaction, birth order, parental expectations, parental differential treatment, and parent-child communication are a few of the factors that have been hypothesized to lead to variable child outcomes.

For example, Rodrigue et al. (1993) reported that the variables of parental marital satisfaction and child birth order influenced behavioral adjustment, including internalizing behavior such as inhibition, shyness, anxiousness or personality problems and externalizing behavior such as aggression and acting out. Older siblings of children with autism had higher rates of both internalizing and externalizing behavioral problems in comparison to younger siblings of children with autism. Also, higher material satisfaction was associated with higher levels of self-esteem in siblings.

Children may also feel that their parents have higher expectations for them in order to compensate for their sibling's inability to accomplish many things. In order to prove to their parents that they can compensate for the disabled child's shortcomings, some children strive to be perfect, both at home and outside the home, by providing extra care for the sibling and by overachieving in activities outside the home (Siegel & Silverstein, 1994). When children attempt perfection in so many areas it may show that they are hard working, but it may also cause much emotional stress. Parents may also treat their typical children differently than their disabled children by giving them more responsibilities around the house, such as chores and child-care responsibilities (McHale & Gamble, 1989).

Bagenholm and Gillberg (1991) found that more than half of the 20 siblings of children with autism that were studied did not have words to explain what was wrong with their brother or sister. This suggests that many parents may not communicating effectively with their children. When parents do communicate openly about the disorder, however, children tend to have fewer worries (Terril, 2000).

Researchers have reported conflicting results describing siblings' characteristics. One study found that siblings of children with autism are at higher risk for becoming depressed than are children with typical siblings (Gold, 1993). McHale et al. (1986) found that sibling relationships of children with autistic, mentally retarded and non-handicapped siblings did not differ significantly, but that variation within the reports of siblings of handicapped children was greater than variation in the control group. These findings indicate that siblings are at risk for social/emotional problems, but that these may be overcome in some situations. Mates (1990) reported more positive results, however, in that 33 siblings of children with autism did not differ from siblings of typical children on performance in academic achievement, self-concept, home behavior and school behavior.

Most of the studies that exist examine possible negative outcomes for the family with or sibling of a child with a disability; however, it is possible that there are some positive aspects of having a child with a disability in that family. For example, Summers and colleagues (1989) conducted interviews with 18 parents who had a child with mental retardation. The researchers found that these parents reported many positive aspects of having a child with a disability in a family, such as: increased happiness, greater love, strengthened religious faith, expanded social network, greater pride and accomplishment, greater knowledge about disabilities, learning not to take things for granted, learning tolerance and sensitivity, learning to be patient, and increased

personal growth. These benefits were reported from families that included a child with mental retardation so it cannot be known if the benefits generalize to other types of disabilities such as autism. Specifically relating to autism and the way the experience of having a sibling with autism is viewed, it has been found that parents' reactions to the child with autism can affect the way that the typical siblings view their disabled sibling. Siblings will be more likely to view their relationship with their sibling who has autism positively when their parents react positively to the sibling. Also, it was found that most siblings reported positively about their sibling regardless of whether or not they were disabled (McHale et al., 1986).

Specific Autism-Related Worries

The variable factors associated with having a sibling with autism may also precipitate worries. These worries may or may not play a role in a child's overall psychological adjustment, so it is useful to examine them separately. Siblings of developmentally disabled children have been found to have higher levels of anxiety than siblings of typical children (McHale & Gamble, 1989). Kuncle and Groh (1998) found that siblings of children with autism reported more autism-specific worries than siblings of typically developing children. A review of the literature has revealed several areas of worries that seem to be prevalent. Siblings worry about the child with autism and the future for that child (Harris, 1994). Parental expectations, communication, and lack of quality time spent can contribute to sibling's concerns (Berkell, 1992). Siblings may also have self-focused worries including concern that they may catch autism or that their sibling may hurt them or their possessions (Kuncle & Groh, 1998; Harris, 1994). Social worries may include anxiety about informing friends, dealing with teasing, friends' acceptance of the disability, and dating. As children mature they may begin to think about implications for the future, including guardianship, financial responsibility, continued involvement, and genetics (Berkell, 1992).

A study conducted by Kuncie & Groh (1998) explored the quantity and intensity of worries in siblings of children with autism and the parent and child agreement about those worries. The participants were 17 children with a sibling diagnosed with autism or PDD NOS (pervasive developmental disorder not otherwise specified) ranging in age from 6 to 14 years old and 16 children with a typically developing sibling. The researchers measured children's worries with the Autism Worries Survey (AWS), a measure they developed based on the clinical and research literature specifically to assess five general areas of concern: (1) self-focused worries, (2) sibling-focused worries, (3) family-focused worries, (4) social worries, and (5) autism-specific worries. All of the children in the autism sample reported at least some autism-related worries. Over half of these participants reported having at least 50 % of the worries on the questionnaire and 29 % of the participants reported having 75 % or more of the worries. Between groups it was found that siblings of children with autism had significantly more overall worries than siblings of typical children. Results also showed that when children reported more intense autism worries, they also reported more generalized anxiety as measured by the Revised Children's Manifest Anxiety Scale. It was also found that parents tended to over-report the total intensity of children's worries, but no differences were found between parents and child-reported total number of worries.

The types of worries that children have appear to be linked with certain developmental stages (Harris, 1994). Developmental understanding is an important factor that can influence the way siblings view their sibling, their family and themselves (Lobato, 1985). Glasberg (2000) performed a study in which siblings were placed into the traditional Piagetian developmental stages of reasoning: *preoperational* (2-7 years old, health problems are caused by a contagion-illness transmitted magically from near objects), *concrete* (7-10 years old, health problems are

caused by contamination-bad thoughts, germs, etc.) and *formal* (10 years old and up, health problems are caused by physiological mechanisms-malfunctioning of body part). It was found that individuals at all three developmental levels functioned at a preoperational level of reasoning when questioned about the definition and etiology of autism, but the maturity of the answers increased in each successive age group, meaning that the older children were in the higher phases of preoperational reasoning. When questioned about the implications of autism for their sibling and for themselves all age groups performed at the expected level of reasoning. It was hypothesized that concepts involving the definition and etiology of autism may be more abstract and harder to grasp than the concrete examples of the implications of the disorder because they can view these every day of their lives. It was also found that siblings often had a lack of information or misinformation regarding the causes of autism. In each age group, preoperational, concrete and formal, it was found that 40%, 18%, and 5% respectively were not actually familiar with the term “autism.” Therefore, it is very important that children are supplied with an accurate, developmentally appropriate explanation for the cause of autism. Otherwise, it has been found that children will often make up their own explanation for the disorder, which may actually be more frightening than the realistic explanation, causing undue worries (Glasberg, 2000).

Sibling Interactions

A recent study that assessed sibling relationship quality found that siblings of autistic children reported less intimacy, prosocial behavior and nurturance than control groups (Kaminsky & Dewey, 2001). In contrast, possible positive aspects such as less competitiveness and quarreling were found between siblings of children with autism and Down syndrome as compared to typical siblings (Kaminsky & Dewey, 2001). As mentioned earlier, however,

Vespo (1995) and Stormshak and colleagues (1996) found in typical siblings that moderate conflict may actually be helpful in developing negotiation skills, affect regulation and behavioral control. If the sibling relationship between the typical sibling and the child with autism does not include much conflict, as reported by Kaminsky and Dewey (2001), these siblings may be fail to benefit from developmentally important conflict situations.

Intervention Efforts

Behavior Modification

Behavior modification programs are focused on increasing and enhancing the play between typical siblings and their siblings with autism. A small number of projects have been performed to study whether or not siblings can be taught to modify their siblings' behavior and the effects this might have (Lobato, 1993). For example, Celiberti and Harris (1993), were able to teach three girls between ages 7 to 10 various skills to play with their younger brothers or sisters with autism. They found that the sibling-trainers were able to generalize skills learned to novel toys and that the skills were maintained until at least 16 weeks after the study. This shows that behavioral treatment can be relatively effective and persistent. Behavior modification, however, cannot stand alone as the only therapy because it is usually expensive since a skilled trainer is required to teach the siblings, the procedure itself is very time-consuming and at times it can be psychologically exhausting for all parties involved. Behavioral techniques also do not specifically address parent-child communication about autism, which is believed to be important in helping to decrease children's worries.

Sibling Support Groups

Sibling support groups have been established in some clinical and school settings in order to give siblings of children with disabilities an opportunity to discuss shared experiences and

learn about their siblings' disabilities. One of the largest sibling support group efforts is Sibshops, which is a nation-wide, non-therapeutic program based on a workshop model designed by Meyer & Vadasy (1994). Sibshops provide siblings of children with disabilities the opportunity to meet and talk with other siblings in a relaxed, recreational setting. The groups focus on learning how to handle situations commonly experienced by siblings of children with special needs and learning more about the implications of their siblings' special needs (Meyer & Vadasy, 1994).

An extensive literature review did not reveal many empirical studies on the effects of sibling support groups. Most reports of the effects of sibling groups are based on anecdotal information (Meyer & Vadasy, 1994). For example, in a group for siblings of children with disabilities Crouthamel, (1988) found that participants reported that in general they had a positive experience. This support group included 12 children ages 7 to 13 years who met for 8 consecutive Saturdays. Activities included watching a videotaped discussion by a group of adult siblings of handicapped persons and developing a newsletter as a way to raise community awareness and educate other siblings who may or may not have a handicapped family member. Dyson (1998) created a program that was designed to meet the needs of school age children ranging in age from 7 ½ to 12 years of age. The goals of the group were to provide children with information about disabilities, social support, opportunities to share experiences, strategies to solve sibling conflicts, and recreational activities. The children in the group had siblings with varying disabilities which included, mental retardation, autism, attention deficit disorders, and sensory impairment. An open-ended questionnaire was meant to assess the children's perceptions of the workshop since no earlier studies had directly asked the children to evaluate the separate elements of a sibling workshop. The questionnaire measured what the children

learned, what they enjoyed, and the times they preferred for the workshop. Children most frequently reported learning how to improve their relationship with their disabled sibling, which included how to help, get along with, and interact with the disabled sibling. Children also reported gaining more awareness of different special needs in general, including appreciation for the experience and strengths of people with disabilities and how to be more helpful to those with disabilities.

An extensive literature review only uncovered two studies that have made use of objective child assessment scales to evaluate indirectly the effects on the siblings' development (Lobato, 1985; McLinden, Miller, & Deprey, 1991). The sibling support group conducted by Lobato (1985) addressed the needs of preschool-aged siblings (ages 3 to 7) for simple explanations of disorders and for personal-emotional support. The results of a role-play assessment indicated that most of their six participants became more accurate in their definitions of specific disabilities and increased in their positive verbalizations regarding their families. Home observations of the children interacting with their disabled sibling indicated that the frequency and quality of interaction remained stable across all experimental conditions. Parents reported that at various points during the program, their children initiated conversations regarding their sibling's disability, which prompted greater discussion about other family issues as well. All parents felt relief and satisfaction in being able to have these open conversations with their child (Lobato, 1995). McLinden et al. (1991) adapted the support group model used by Lobato to be appropriate for school age children. Results indicated that the support group had a significant effect on children's perception of the social support they received, but it did not on other measures of child functioning. A parent interview also indicated that there were some improvements in the participants' behavior towards their sibling. McLinden et al. (1991)

concluded that the program offered limited success in that it did not have any significant effect on children's behavior problems, self-concept, knowledge or attitudes.

Although many interventions appear to be successful, there are several limitations that characterize the support group research studies. The samples are often small and heterogeneous, including siblings of children with myriad disorders. Also, researchers typically have not used objective measures, included control groups, or involved parents.

Current Study

The current study builds upon results from several studies conducted at Illinois Wesleyan University (Kunce & Groh, 1998; Kunce, Holsen, & Suhr, 1999). Specifically, it modifies a design used by Terril (2000) in which the effects of a parent-child communication activity were examined. The researchers contrasted the effects of a specific parent-child communication workbook to a free-play placebo condition to assess whether the workbook led to a decrease, an increase, or no change in children's autism-related worries. The results showed that on average, children in the workbook condition reported fewer worries than did the children in the free-play condition, but there was no significant difference between the two groups. The small sample size of eight children per group may have decreased the chance of finding significant results. Parents were also more accurate at assessing their child's worries after both activities, although this finding was more marked in the workbook condition. The workbook may have also slightly increased the quality of autism communication.

Based on the results of this past study, the current study was proposed in order to continue data collection on the efficacy of the parent-child communication activity in reducing children's worries. Several hypotheses about the outcome of the current study are stated below:

First, it was hypothesized that children's autism-related worries would be lower in the workbook condition in comparison to the games condition.

Second, it was hypothesized that parents would be able to predict their children's worries more accurately in the workbook condition as compared to the games condition.

Third, it was hypothesized that by parents and children would report improved autism-specific communication in the workbook condition as compared to the games condition.

Two additional exploratory analyses of group differences will be conducted on children's self-efficacy as measured by a coping scale and on children and parent's perception of the sibling relationship quality.

Method

Participants

Participants included 18 children (15 boys and 3 girls) who were 6-13 years-old, $M = 9.39$, $SD = 1.78$, and majority were Caucasian (78%). Seventeen parents participated (i.e., one parent worked with one child, except one mother worked with two children). Parents reported that the siblings with autism all had autism-spectrum disorders, and most were mild (35%) to moderate (59%) severity. The gender ratio for the siblings with autism was boys to girls 4:1, which is what has been reported as the national ratio. Approximately 250 recruitment letters were distributed through autism support groups and school programs in Bloomington, IL, Chicago, IL, and the St. Louis, MO area. On the demographics questionnaire, some parents indicated that they had never attended a support group (35%) while other parents indicated attending a support group once a month or more (59%). Seven parents reported that their children had never attended a sibling support group (38%), while only three children attended sibling support groups each month (17%). Before participating in the study, several of the

parents (38%) reported never speaking to their children about autism in the past month.

Demographics describing more about participating children, siblings with autism, parents, and support group information are shown in Table 1.

Child Measures

Child Activity Evaluation Form. This simple measure, originally developed for use in the earlier sibling intervention study (Kunce & Terril, 2000), includes two items that assess the children's perceptions of the activity. The children's scale was based on a 4-point scale that ranged from a score of 1, "I really didn't like it," to a score of 4, "I really liked it." The internal consistency of this measure was somewhat low, but acceptable for research purposes, $\alpha = 0.64$.

Autism Worries Survey (AWS). Children completed this 50-item survey, which was used in other studies at Illinois Wesleyan University (e.g., Kunce & Terril, 2000; Kunce Holsen, & Suhr, 1999; Kunce & Groh, 1998). Each item presents a statement in the format "*Some kids worry that...*". For example, "Some kids worry that they will catch their brother's or sister's autism." The child responds by indicating the degree of his or her worry about the item on a 4-point scale that ranges from "this child really worries," to "this child doesn't worry". A 10-item version of the AWS, called the AWS-Short Form, was given as a pretest measure to children in both groups and as a follow-up measure, which was included in a phone survey. When scoring the measure, if the child indicated having any degree of worry, then that was counted as an endorsed worry. The intensity was measured on a 4-point scale, with four being the highest degree of worry. The internal consistency of the AWS-Short Form was high ($\alpha = 0.84$), and the internal consistency of the AWS was excellent, $\alpha = 0.96$.

Autism Communication Scale-Revised (ACSR). This 5-item survey was developed specifically for use in the current study. The survey was loosely based on a previous 10-item

Autism Communication Scale used in a previous sibling intervention study (Kunce & Terril, 2000). This earlier measure did not show internal consistency, which is why the new measure was developed. In each ASCR item two children with differing views were presented and the children were asked to first, choose which child they were most like, and second, to decide whether they were a lot like them or a little like them. For example, the first item presents “Sam” who talks a lot to his parent about autism worries and “Alex” who never talks to his parent about autism worries. Once the child decides if they are more like Sam or more like Alex, then they are asked to decide if they are a lot like that child or a little like that child. This measure had high internal consistency, $\alpha = 0.85$.

Coping Scale. This is a 10-item survey created for this study in which children were asked how well they think they could handle certain situations. It was designed to measure children’s feelings of self-efficacy. Children were given a choice between three responses, 1) I could not handle this, 2) I could sort of handle this, or 3) I could handle this very well. An example of one item is, “If my brother or sister misbehaves in public.” Children’s evaluations were on a 3-point scale that ranged from 0 to 2, with 2 representing the highest degree of coping. The measure had acceptable internal consistency, $\alpha = 0.77$.

Sibling Relationship Questionnaire-Revised (Child). (Furman, 1990). This well-developed and frequently used measure consists of 16 scales containing 2-3 items each, with a total of 48 items that assess children’s perceptions of their siblings. A subset of these scales measuring the constructs of warmth and conflict were given to the children so that they answered a total of 30 questions.

Parent Measures

Parent Activity Evaluation Form: Treatment Evaluation Inventory-Short Form. (TEI).

This is a frequently used 6-item measure assessing consumer perceptions of intervention techniques. This scale range from a score of 1, “Strongly Disagree,” to a score of 5, “Strongly Agree.” Internal consistency for this measure was acceptable, $\alpha = 0.75$.

Demographics Questionnaire. Parents completed a brief demographics questionnaire about themselves and their children. This form asks questions about factual data (e.g., parent age, child gender), as well as about family communication and use of support services.

Autism Worries Survey (Parent Form). This is a parallel version of the full 50-item AWS that the children completed. Questions were reworded so that the parents predict their child’s worries. Parents were not given the shorter 10-item AWS before treatment as the children were, because in the previous study it was found that parents in the control group still talked to their children about their worries even though they were encouraged not to do so. Parents were also given a fifth option that said “don’t know,” if they could not predict their child’s worry for a certain item. Internal consistency of this measure was excellent, $\alpha = 0.94$.

Autism Communication Scale (ACS). Developed for use in the previous sibling intervention studied conducted by Kuncie & Terril (2000), this 5-point scale includes eight items that assess parent-child communication about autism and one item that assessed the parent’s satisfaction with their autism-related communication with their child. The internal consistency of this measure was somewhat low, but acceptable, $\alpha = 0.68$.

Child Behavior Checklist. (CBCL; Achenbach & Edelbrock, 1983). This is a reliable, frequently used questionnaire that assesses children’s internalizing and externalizing problems.

Sibling Relationship Questionnaire-Revised (Parent). (Furman, 1990). This measure parallels the child version and parents were given the same scales as children. The 30 items assessed the parent's perception of the sibling relationship between the typical child and the child with autism.

Procedure

Pretest Phase: The parent-child pairs participated in an activity/research session, which lasted about two hours. First, children and parents met in a large group to obtain informed consent and assent. Then, the parents and children went to separate rooms and the children completed the AWS-Short Form pretest measure while the parents received instructions for carrying out the planned activities.

Intervention Phase. The child-parent pairs were randomly assigned to either the workbook or games condition. These groups met in separate rooms for the active part of the study. In each group, the parent actively engaged with the child for approximately 45 minutes. The activities for each of these were as follows:

Intervention group: Parents were able to examine sample workbook questions and ask questions before completing it with the child. If they felt that the activity was not appropriate for their child they would have been able to withdraw from the study without prejudice, however, there were no families that did so. It was emphasized to parents that this was a preliminary study; the workbook was only used a few times before, so it could not be considered a proven treatment. Parents were also given the "Parent Instruction Handout: Tips for Completing the Autism Workbook with your Children," which encouraged them to avoid responding in a judgmental manner and to take breaks as needed during the activity. In addition, both parents and children were reminded that they could skip any questions that they are not comfortable

answering. The parent and child completed a workbook designed to help the child communicate his or her autism worries to the parent. The first portion of the workbook contains 33 items that ask about autism-related worries. The second portion of the workbook contains eight vignettes to help parents and children discuss and develop coping techniques for different concerns.

Control group: The parents and children played games together, selecting from games provided by the researchers (e.g., cards, checkers, Chutes and Ladders, Clue, etc.). Prior to interacting with their child, parents were able to look over the games and ask questions about the activity. They were also given the “Parent Instruction Handout: Tips for Games Activity,” which encouraged them to keep their focus on their child and to take breaks as needed during the activity.

Post-Test Phase. After the 45 minute activity, the parents and children went to separate rooms to complete the dependent measures. A research assistant helped the children complete the measures and another research assistant stayed with the parents in case they had any questions while filling out the measures. At the end of the session parents and children were provided with debriefing sheets that recommend ways to address children’s autism-related worries as well as suggestions about how to continue the workshop activities at home. As a token of appreciation, both children and parents were provided with snacks during the activities and the children received a small gift at the end of the session.

The families were contacted by phone three to four weeks after the workshop and both the child and the parent were asked the 10-item version of the Autism Worries Survey. In addition, a few questions were asked about their follow-up activities and experiences. So that the families could try the activity they did not complete during the study, after the phone call,

directions were sent for the activity that they did not complete during the study. Parents were provided with a summary of the results of the project.

Results

Pretest Comparisons

Pretest measures were given in order to check for equivalence of groups prior to the intervention. T-test analyses showed that there was not a significant difference between groups on child age, $t(16) = 0.69, p = 0.50$, age of the sibling with autism, $t(15) = 1.48, p = 0.16$, or age difference between the typical child and the child with autism, $t(16) = -0.97, p = 0.35$ (see Table 2 for the means, standard deviations, and gender ratios for intervention groups).

When analyzing the results of the Autism Worries Survey-Short Form, both the number of worries endorsed and the intensity of worries were examined. The mean number of worries reported by children in the workbook ($M = 4.44, SD = 3.05$) did not differ significantly from those reports by children in the games, $t(16) = -1.14, p = 0.27$. Similarly, the mean intensity of worries in the workbook ($M = 1.83, SD = 0.75$) did not differ significantly from those reports by children in the games, $t(16) = -0.10, p = 0.33$. There was also no difference between the groups on their total scores from the Child Behavior Checklist, $t(16) = -0.85, p = 0.41$.

Child Worries

Similar to the results reported by Kuncé & Groh (1998), the number of children endorsing 50% or more of worries was 50%, while the number of children endorsing 75% or more of worries was 22%. The first major hypothesis for the current study was that children's autism-related worries would be lower in the workbook condition in comparison to the games condition (means and standard deviations for child and parent report of number and intensity of worries can be found in Table 3). This hypothesis was not supported as t-tests demonstrated that

there was no difference between children reports in the two groups for both number of worries, $t(16) = -0.27, p = 0.79$, and intensity of worries, $t(16) = -0.79, p = 0.44$. Parents' perception of children's worries in both groups were also examined and no significant difference was found for either number of worries, $t(16) = 0.12, p = 0.91$, or for intensity of worries, $t(16) = -0.37, p = 0.72$.

Parent-Child Accuracy

Second, it was hypothesized that parents would be able to predict their children's worries more accurately in the workbook condition as compared to the games condition. This hypothesis was supported with a strong significant correlation in the workbook condition between the number of children reported worries and the number of parent reported worries, $r(9) = 0.85, p < 0.01$, however, there was no significant correlation in the games group, $r(9) = -0.21, p = 0.58$. A marginally significant correlation between the child and parent report of intensity was found, $r(9) = 0.66, p = 0.051$, in contrast, no significant correlation was found in the games group, $r(9) = -0.15, p = 0.70$. A Fisher's r to z transformation was used to test for differences between the correlations for both number and intensity. The correlations for number of worries were found to be significantly different, $F = 2.54, p < 0.05$, however, the correlations for intensity of worries were not found to be significant, $F = 1.63, ns$. An additional approach to examining parents' accuracy was to look at the number of parents that chose the "don't know" option on the AWS. It was interesting that out of the 17 parents, 4 parents in the games group reported not knowing how to predict certain items; all other parents attempted to answer every question. It was interesting that out of the four fathers in the study that the two fathers in the games group responded "don't know" to the most worries out of all the parents, with 24 and 16.

Autism Communication

Third, it was hypothesized that parents and children would report improved autism-specific communication in the workbook condition as compared to the games condition. This hypothesis was not supported as t-tests showed that there was no significant difference between the communication as reported by the children in the workbook ($M = 3.00, SD = 0.66$) or the games conditions ($M = 2.98, SD = 0.94$), $t(16) = 0.06, p = 0.96$. There was also no difference between the communication as reported by the parents in the workbook ($M = 4.04, SD = 0.60$) or the games conditions ($M = 4.12, SD = 0.76$), $t(16) = -0.26, p = 0.80$.

Treatment Acceptability

No significant difference was found between the workbook, $M = 3.67, SD = 0.43$, and the games, $M = 3.94, SD = 0.17$, groups for children's assessment of treatment acceptability, $t(10.32) = -1.80, p = 0.10$. The children's scale was based on a 4-point scale and the means show that they rated both activities between "I really like it" and "I liked it somewhat." There was also no difference between the workbook ($M = 4.04, SD = 0.50$) or games ($M = 3.93, SD = 0.50$) groups for the parents' assessment of treatment acceptability, $t(16) = 0.47, p = 0.64$. The parent's scale was based on a 5-point scale in which 3 responded to "neutral", 4 responded to "agree" and 5 responded to "strongly agree." An example of a question on the parent activity evaluation was, "I believe that this activity is likely to be effective as a way to decrease my child's worries."

Additional Group Comparisons

Coping. No significant difference was found between the two groups in their feelings of self-efficacy, $t(16) = 0.46, p = 0.64$.

Sibling Relationship. A non-significant group difference was found for the children on both warmth, $t(16) = -0.26, p = 0.80$ and conflict, $t(16) = 1.12, p = 0.28$. Similarly, the parent report of the sibling relationship did not differ for either warmth, $t(16) = 0.08, p = 0.94$, or conflict, $t(16) = 1.16, p = 0.26$.

Discussion

Siblings of children with autism face many special challenges that may cause them to worry about things that typical children do not worry about (Kunce & Groh, 1998). Numerous clinical interventions have been developed (Meyer & Vadasy, 1994), but limited empirical research is available on the effectiveness of such interventions. In an effort to address this gap in the literature and to clinically address these children's worries, this study was designed to obtain objective results about the effects of two different parent-child activities on the siblings of children with autism. The study used an experimental design to compare a group of parent-child pairs that used the autism worries workbook with a group that played board games. The main variables that were examined were the number and intensity of child worries, the accuracy of the parents' report of children's worries and the parent and child report of autism communication. One of the three hypotheses that were stated for these variables was supported.

The first hypothesis was that children's autism-related worries would be lower in the workbook condition in comparison to the games condition, contrary to hypotheses, results showed that the workbook and the games did not differ in the amount or intensity of worries that children reported after the activity. Thus, it appears that the brief intervention was not sufficient for changing immediate perception of worries as reported by the children or parents. In retrospect, this finding is not surprising considering that the intervention was only a 45 minute activity and the children completed the dependent measures immediately after the activity. That

is, worries might not be expected to change in response to a brief one-time intervention, however, differences may be found across a longer intervention or a follow-up period. Our results were consistent with other findings, however, in that siblings of children with autism tend to be highly variable in their characteristics as demonstrated by one child who endorsed only 1 worry and another child who endorsed 45 worries (McHale, Sloan, Simeonson, 1996). .

The second hypothesis was that parents would be able to predict their children's worries more accurately in the workbook condition as compared to the games condition. This hypothesis was supported in that the correlation between parent and child report of child worries was significantly higher in the workbook condition, than in the games condition. The workbook was therefore useful in making parents more aware of their children's specific worries. Over time, the increase in parents' awareness of their children's problems may help them to better understand their children and better assist them in coping with their worries. As a result, children may be less susceptible to the possible problems suggested by other studies, such as internalizing and externalizing behaviors and depression (Rodrigue et al., 1993; Gold, 1993):

The third hypothesis was that parents and children would report improved autism-specific communication in the workbook condition as compared to the games condition. Results showed that participants in the workbook and the games conditions did not differ in the report of autism communication. The questionnaires asked about communication in general (i.e. "My child can talk to me about his/her sibling with autism"). Thus, it appears that the brief intervention was not sufficient for changing immediate perception of global communication. In contrast, a difference may have been observed if more specific questions about communication on the day of the intervention had been asked, such as, "Did you learn something about your child today that you

did not know before?” or “Did this activity help you to talk to your parent about your worries about autism?”

Additional analyses were conducted to examine possible effects on coping and the sibling relationship quality. No difference between the groups was found for the coping scale. A difference may have been found if children and parents had more time to discuss the second half of the workbook, which presented eight vignettes about various problems and it prompted parents and children to talk about how the children could handle those problems. Most parent-child pairs completed two or three of the vignettes, but it was not recorded which vignettes they completed, as this was not a major goal of the study. In the future, it may be helpful to have an intervention that is long enough for the parents and children to complete the entire coping section of the workbook and have them complete a coping measure based on specific vignettes addressed in the workbook.

Another additional analysis was examining the warmth and conflict scales in the sibling relationship questionnaire, since it has been found in previous research that sibling warmth and moderate conflict can both play a role in typical child development (Vandell & Bailey, 1992; Vespo, 1995). No difference was found between the child or parent groups in sibling relationship warmth and conflict, most likely because the workbook intervention was not designed to specifically address sibling-to-sibling issues.

Overall, both parents and children had a positive reaction to both activities. This demonstrates that the activities are acceptable and enjoyable for both children and parents. These positive evaluations are important because it shows that children do not mind participating and there are no evident harmful effects and it shows that parents viewed the games as a parallel treatment (i.e., effective placebo).

The study had some strengths in comparison to weaknesses in some past research. One strength was that there was random assignment to groups, which allowed for between-group comparisons, whereas other studies only included descriptions of one group (Crouthamel, 1988, Dyson, 1998, McLinden, 1991). The sample was also slightly larger than in previous studies and it was homogeneous in that it included only siblings of children with autism, instead of siblings of children with varied disabilities (Bagenholm & Gillberg, 1991). In addition, the study used the Autism Worries Survey, which is an objective measure with very high internal consistency and evidence of construct validity (Kunce & Terril, 2000), whereas previous research used only subjective measures (Crouthamel, 1988; Dyson, 1998). One final strength was that the parents were involved in the activities; none of the other studies involved parents directly in the activities. This is important for two reasons, first, it allowed for validation of the child's worries as reported by both the parents and the children and second, it may be important to have the parents be involved so that they can help the child cope in their day-to-day family struggles.

The study also had certain limitations. One limitation was the length of the intervention, which was approximately two hours. For future research it would be interesting to employ a longer intervention that was possibly more intense or extended over a longer period of time. A long-term study that would be especially important may be to examine siblings from a developmental perspective as they grow and develop more mature understanding of autism. Other limitations related to the characteristics of the sample. There was self-selection bias in that participation in the study was voluntary and less than 10% of families contacted about the study decided to participate. In addition, the sample was relatively homogeneous in that 14 of the children were Caucasian, all but one parent was married, and all of the parents at least had a high school education. Two other limitations of the sample was that it was relatively small and it

contained mostly boys. It could be possible for some reason that parents were more concerned about their boy siblings' worries than their girls' worries.

Siblings of children with autism face many challenges that may cause them to have more worries than typical children. This study was designed to help alleviate those worries and increase parents' awareness of those worries. The initial results are promising in that it was shown that parents were actually able to predict their children's worries more accurately after completing the workbook. Future research should concentrate on obtaining long-term data for a larger and more heterogeneous sample.

Table 1

*Demographics Information*Typical Siblings ($N = 18$)Age $M = 9.39$, $SD = 1.78$, range: 6-13

Gender 3 girls (17 %), 15 boys (83 %)

Ethnicity 14 Caucasian (78 %), 2 Mixed Ethnicity (11 %), 2 Other (10 %)

Support Groups (per year) $M = 2.67$, $SD = 4.41$, Median = 1, Mode = 0, Range = 0-12Autistic Sibling ($N = 17$)Age $M = 9.53$, $SD = 3.21$, range: 4.4-15.4

Gender 3 girls (18%), 14 boys (82%)

Diagnosis Autism: 6 (35%)

High Functioning Autism/Asperger's Disorder 6 (24%)

PDD-NOS: 5 (29%)

Parent-Reported Severity Mild: 6 (35 %), Moderate: 9 (59 %), Severe: 1 (6 %)

Parents ($N = 17$)

Age Range 20-30 (1); 31-40 (9); Over 40 (7)

Gender 13 females (76%), 4 males (24%)

Marital Status Married: 16, Divorced: 1

Education $M = 15.4$ years, $SD = 2.5$, range: 12-19

Relationship to child in study 17 birth parents

Support Groups (per year) $M = 8.19$, $SD = 7.08$, Median = 12, Mode = 12, Range: 0-24Prior Autism Communication $M = 3.29$, $SD = 5.39$, Median = 2, Mode = 0, Range: 0-20
(past month)

Table 2

Means, Standard Deviations, and Gender Ratios for Intervention Groups

	Workbook	Games	T-test/Total Ratio
Participating Child Age	9.69 (1.94)	9.10 (1.68)	$t(16) = 0.69, p = 0.50$
Autistic Sibling Age	10.58 (3.82)	8.33 (1.87)	$t(15) = 1.48, p = 0.16$
Age Difference	-0.90 (4.74)	0.77 (2.09)	$t(16) = -0.97, p = 0.35$
AWS-Short Form			
Number	4.44 (3.05)	5.89 (2.26)	$t(16) = -1.14, p = 0.27$
Intensity	1.83 (0.75)	2.17 (0.66)	$t(16) = -0.10, p = 0.33$
CBCL Total	47.78 (11.03)	52.67 (13.27)	$t(16) = -0.85, p = 0.41$
Boys : Girls	8:1	7:2	15:3
Fathers : Mothers	2:7	2:6	4:13

Note: Number represents the number of endorsed (yes/no) worries (maximum of 10).

Intensity represents mean intensity of worries on a 4-point scale, with 4 representing the highest degree of worry.

Seventy is the cutoff for clinical behavior problems for the CBCL.

Table 3

Means and Standard Deviations for Total Number and Intensity of Child Worries for AWS

	Workbook	Games	T-Tests
Number			
Child	22.89 (14.46)	24.56 (11.99)	$t(16) = -0.27, p = 0.79$
Parent	24.67 (13.18)	24.00 (10.39)	$t(16) = 0.12, p = 0.91$
Intensity			
Child	1.78 (0.63)	2.03 (0.71)	$t(16) = -0.79, p = 0.44$
Parent	1.88 (0.56)	1.89 (0.46)	$t(16) = -0.37, p = 0.72$

Note: Number represents the number of endorsed (yes/no) worries (maximum of 50).

Intensity represents mean intensity of worries on a 4-point scale, with 4 representing the highest degree of worry.

Table 4

Means and Standard Deviations for Additional Group Comparisons

	Workbook	Games	T-Tests
Coping	1.23 (0.39)	1.13 (0.49)	$t(16) = 0.47, p = 0.64$
SRQ-Child			
Warmth	2.85 (0.62)	2.97 (1.21)	$t(16) = -0.26, p = 0.80$
Conflict	3.20 (1.01)	2.70 (0.85)	$t(16) = 1.12, p = 0.28$
SRQ-Parent			
Warmth	2.81 (0.73)	2.78 (0.66)	$t(16) = 0.08, p = 0.94$
Conflict	2.45 (0.63)	2.02 (0.91)	$t(16) = 1.16, p = 0.26$

Note: Coping was evaluated on a 3-point scale that ranged from 0 to 2, with 2 representing the highest degree of coping.

The SRQ was evaluated on a 5-point scale with 5 representing the highest agreement.

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Appendix

Autism Worries Workbook-Sample Page

Autism Worries Survey (AWS)-Sample Page

Worries About Being Treated Differently in Your Family

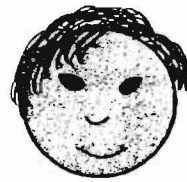
1. Some kids worry that their parents love their sister or brother more than them.



This child
really worries

☐

This child
kind of worries

☐

This child worries
just a little bit

☐

This child
doesn't worry

☐

Which child are you most like?

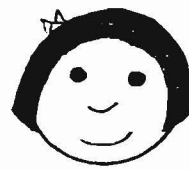
2. Some kids worry that they don't get enough attention, time, or money from their parents because of their sister or brother.



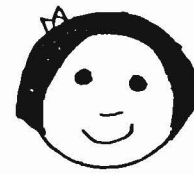
This child
really worries

☐

This child
kind of worries

☐

This child worries
just a little bit

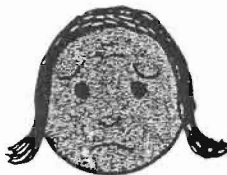
☐

This child
doesn't worry

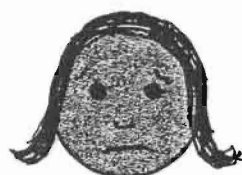
☐

Which child are you most like?

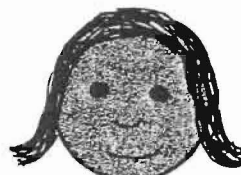
3. Some kids worry that they have more chores to do around the house because their sister or brother has autism.



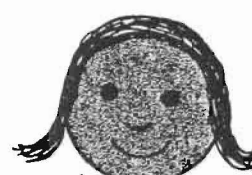
This child
really worries

☐

This child
kind of worries

☐

This child worries
just a little bit

☐

This child
doesn't worry

☐

Which child are you most like?

This
child
really
worries.



This
child
kind of
worries.



This
child
worries
just a
little bit.



This
child
doesn't
worry.



Which one are you most like?



My brother/sister with autism is _____

1. Some kids worry that they might catch autism from their brother or sister.
2. Some kids worry that they will get punished because of something their brother or sister did.
3. Some kids worry that something they did or said or thought made their brother or sister have autism.
4. Some kids worry that their brother or sister will hurt themselves.
5. Some kids worry that their parents don't love them as much as they love their brother or sister. (6)
6. Some kids worry that other kids tease them about their brother or sister. (8)
7. Some kids worry that they will have to take care of their brother or sister when they are older. (10)
8. Some kids worry that they might have autism like their brother or sister. (11)
9. Some kids worry that their brother or sister will break their things. (12)
10. Some kids worry that they get angry at their brother or sister too much. (13)