

Integrated Sibling-Parent Group Intervention to Improve Sibling Knowledge and Adjustment to Chronic Illness and Disability

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Objective: To evaluate an integrated group intervention for siblings and parents designed to increase sibling understanding of and adjustment to chronic illness and developmental disability (CI/DD).

Methods: Fifty-four well siblings (ages 8–13 years) and their parents were recruited through hospital-based and community agencies serving children with CI/DD. Measures of sibling knowledge, sibling adjustment to the disorder, sibling connectedness, and sibling global behavioral functioning were collected before and after the intervention. A subsample of 20 families completed a 3-month follow-up to assess maintenance of results.

Results: Sibling knowledge of the child's disorder and sibling connectedness increased, while sibling reports of negative adjustment to the disorder and parent reports of sibling global behavioral functioning decreased significantly from pre- to posttreatment for both boys and girls, regardless of the type of diagnostic condition. Improvements in sibling knowledge, connectedness, and behavioral problems maintained at 3-month follow-up. Parent satisfaction with the program was high.

Conclusions: Results support the future conduct of more controlled evaluation of the integrated sibling and parent group intervention model to improve sibling knowledge of and adjustment to CI/DD.

Key words: *siblings; chronic illness; disability; family treatment; group therapy.*

Siblings of children with chronic illnesses and developmental disabilities (CI/DD) are two to three times more likely than their peers to experience psychological adjustment problems (Cadman, Boyle, & Offord, 1988; Sahler et al., 1994). Within their families, siblings may experience extra caregiver burden, differential treatment, and an imbalance of family resources (McHale & Gamble, 1989; Quittner & Opiari, 1994). Outside their families, siblings may experience limited access to information about the

child's condition, negative peer reactions, and disruptions in social activities (Bluebond-Langner, 1996).

Psychoeducational sibling group interventions have been developed to improve sibling knowledge of and adjustment to chronic illnesses or disabilities (e.g., Lobato, 1990; Meyer & Vadasy, 1993). Empirical evaluations of sibling programs demonstrate pre-post increases in siblings' knowledge of the child's condition and high consumer satisfaction ratings (e.g., Dolgin, Somer, Zaidel, & Zaizov, 1997; Williams et al., 1997). Few studies have measured sibling emotional or behavioral functioning secondary to group

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treatment and the results are not conclusive (Dolgin et al., 1997; McLinden, Miller, & Deprey, 1991).

Despite evidence that sibling and parent adjustment are interrelated (Fisman et al., 1996), parents typically have not been incorporated into sibling group interventions. Thus, the purpose of this project was to develop and evaluate an integrated group intervention for siblings and parents of children with CI/DD that we entitled "SibLink." The intervention focused on 8–13-year-old siblings, as this age group has received the greatest attention in the sibling literature (Stoneman & Berman, 1993). This article presents the preliminary evaluation of the intervention on the primary SibLink goals of improving sibling knowledge, sibling adjustment to CI/DD, and siblings' sense of connectedness to other children in similar family circumstances (hereafter referred to as "sibling connectedness").

Method

Recruitment

SibLink was offered as an outpatient service at a northeast urban children's hospital. Families responded to flyers or to informational meetings at the hospital clinics and at local community agencies serving children with CI/DD. Participants were neither solicited nor excluded on the basis of identified sibling behavioral problems. Families whose children were in the end-stage of illness or who had been diagnosed less than 6 months prior to the study were excluded. Parent consent and sibling assent were obtained prior to participation in the research, which had approval of the hospital's institutional review board.

Participants

The sample consisted of 54 well siblings (24 boys, 30 girls) and their 47 parents (in seven cases, two well siblings from the same family participated). The siblings ranged in age from 8 to 13 years (M age = 9.8 years). Approximately half of the siblings (57%) were older than the child with CI/DD. The children with CI/DD (33 boys, 14 girls) ranged in age from 1 to 16 years (M age = 8.7 years) and were diagnosed with the following types of disorders: physical disabilities (26%), autism spectrum disorders (23%), mental retardation (21%), medical disorders (17%), or com-

bined psychiatric and learning disorders (13%). The majority of the siblings were from two-parent or stepparent (87%), Caucasian (89%) families. Most families (89%) contained two or three children. Most families (65%) were at a technical or professional level, with a median annual income of \$50,000 plus.

Evaluation Procedures

Pre- and Posttreatment. Within 2 weeks preceding the first group meeting, parents and siblings completed separate structured interviews and questionnaires. All questionnaire items were read aloud to each child; parents completed written questionnaires independently. Siblings and parents returned for post-treatment evaluation within 2 weeks of the last group session. The same parent (94% mothers) completed the pre- and postevaluation questionnaires.

Three-Month Follow-Up. In the last 2 years of the project, we received funding from a private foundation to conduct an additional evaluation 3 months posttreatment. Of the 30 families who participated during this time period, 20 completed the extra post-3-month evaluation and were compensated \$20.00. There were no significant differences in demographics between the 20 families who completed the 3-month follow-up, the families who declined the follow-up, or the rest of the sample.

Evaluation Measures

Sibling Knowledge of CI/DD. A structured interview and scoring system (available upon request) were developed to assess the level of accuracy of siblings' knowledge of their brother/sister's disorder in terms of knowing the name of the disorder and being able to explain it. First, siblings were asked to name the child's disorder. Responses were coded on a scale of 1 to 3, ranging from not knowing the name to stating a specific and accurate term. Siblings were then asked to explain the child's disorder in terms of characteristics such as core symptoms and treatment. Siblings' ability to explain the condition was coded on a scale of 1 to 5, ranging from no understanding to accurate understanding. To assess interrater reliability, two coders independently rated 18% of the sibling responses to the knowledge interviews. Coders were blind to participant identity and time of evaluation. Chance-corrected agreement (κ) was 100% for name of the disorder and 89% for explanation of the disorder.

Sibling Adjustment to CI/DD. The Sibling Perception Questionnaire (SPQ) was originally developed to measure school-age siblings' responses to childhood cancer (Sahler & Carpenter, 1989). The four original subscales of the SPQ assess sibling interpersonal relationships, intrapersonal responses, fear, and communication about the illness. The SPQ has been adapted for use with siblings and parents of children with other diagnostic conditions by replacing the word "cancer" with generic terms such as "problem" (Hodapp, Wijma, & Masino, 1997). Siblings completed the adapted SPQ by rating items on a scale of 1 (never) to 4 (a lot). In order to assess parent perception of sibling adjustment to CI/DD, we created a parent version of the SPQ (available upon request) on which parents completed items parallel to those of the sibling SPQ. Due to low individual subscale reliabilities for the four original subscales for both siblings and parents, we combined the interpersonal, intrapersonal, and fear subscales to form an 18-item composite Negative Adjustment scale on which higher scores reflected more negative sibling adjustment to CI/DD. The alpha coefficients for the composite Negative Adjustment scale were .79 (siblings) and .74 (parents).

Sibling Connectedness. Siblings and parents responded to a three-item questionnaire (available upon request) to assess sibling sense of connectedness (e.g., "I have met other kids with brothers or sisters who have problems"). Each item was rated on a 4-point Likert scale ranging from "1 = never" to "4 = a lot." Internal consistency of the measure of sibling connectedness was .73 (siblings) and .86 (parents). The mean scale score was used in analyses.

Sibling Global Behavioral Functioning. The Child Behavior Checklist Ages 4–18 (Achenbach, 1991) was administered at pretreatment to obtain a measure of global behavioral functioning that could be used to compare our sample to normative groups as well as to previous sibling research samples. Additionally, anticipating the possibility of mixed responses to the idea of bringing children together to discuss disability-related issues, the CBCL was repeated at post- and 3-months-posttreatment to monitor for any negative side effects of group participation.¹

Participant Satisfaction. At posttreatment, parents anonymously rated their overall satisfaction with

¹Secondary measures of sibling self-perception and sibling dyadic relationship quality also were collected pre- and posttreatment to monitor potential negative side effects of group participation, of which there were none. Details regarding these analyses are available from the authors on request.

the intervention on a scale from 1 = "not at all satisfied" to 5 = "very satisfied."

Treatment

The SibLink intervention consisted of six 90-minute group sessions conducted over a 6–8-week period and detailed in separate parent and sibling group treatment manuals (available upon request). Two sessions targeted improving sibling knowledge and family information exchange. Two sessions targeted identifying and managing sibling emotions with problem-solving around challenging situations. One session focused on balancing siblings' individual needs. The final session provided a review and graduation ceremony.

Nine groups containing an average of six siblings were led by two doctoral level trainees in psychology or psychiatry. Activities of the sibling group alternated between explicitly focused "main events" and other more social-recreational activities that addressed the goals of enhancing sibling connectedness more implicitly. Some sibling group activities resembled elements of existing sibling curricula (Lobato, 1990; Meyer & Vadasy, 1994); most activities were original.

Collateral parent groups consisted of 5–6 parents led by a licensed clinical psychologist. The parent group "main events" involved a mix of didactic presentation, meeting with adult siblings of a child with a disability or illness, and group discussion on topics that paralleled those of the sibling group. Additionally, activities of the sibling and parent groups were integrated to enhance mutual understanding and perspective taking. Siblings created a videotape about their experiences that parents reviewed, and sibling and parent groups joined for portions of four of the sessions to visit the hospital library, read books, engage in interactive exercises and games, and to participate in the graduation.

Results

All enrolled families completed treatment. Attendance rates for siblings and parents were high with 75% of the families attending all six sessions. Parent ratings of satisfaction with the program were high (average 4.5 on a scale from 1–5). All 54 of the siblings completed pre-post data, whereas parents of 9 of the siblings did not have complete pre-post parent

Table 1. Mean Scores on Outcome Measures at Pre-, Post-, and 3 Months Posttreatment

Measures	Full Sample (<i>n</i> = 54)		Follow-Up Sample (<i>n</i> = 20)		
	Pre-Tx <i>M</i> (<i>SD</i>)	Post-Tx <i>M</i> (<i>SD</i>)	Pre-Tx <i>M</i> (<i>SD</i>)	Post-Tx <i>M</i> (<i>SD</i>)	3 Months Post-Tx <i>M</i> (<i>SD</i>)
Sibling knowledge					
Name	2.2 (0.85)	2.6 (0.74)**	2.3 (0.86)	2.6 (0.76)	2.6 (0.75)
Explanation	4.0 (0.89)	4.5 (0.69)**	4.0 (0.94)	4.6 (0.69)	4.2 (0.88)*
Sibling Perception Questionnaire (SPQ): Negative Adjustment Composite					
Sibling report	2.3 (0.42)	2.2 (0.47)*	2.2 (0.46)	2.2 (0.51)	2.1 (0.39)
Parent report	2.6 (0.37)	2.5 (0.31)	2.5 (0.37)	2.4 (0.33)	2.4 (0.40)
Sibling connectedness					
Sibling report	2.1 (0.76)	2.9 (0.77)**	2.0 (0.85)	2.8 (0.78)	2.7 (0.79)**
Parent report	2.0 (0.91)	2.8 (0.82)**	1.8 (1.01)	2.8 (0.87)	2.6 (0.44)**
Child Behavior Checklist					
Internalizing <i>T</i>	55 (9.86)	51 (9.88)**	52 (9.45)	50 (9.93)	49 (10.03)*
Externalizing <i>T</i>	54 (10.07)	51 (10.90)**	53 (10.77)	51 (12.77)	50 (12.04)*

p* < .05.*p* < .01.

data. There were no significant group differences in the demographic characteristics of the families with and without complete pre-post parent data.

Pre-Post Evaluation

All dependent variables completed at pretreatment were normally distributed. Repeated measures analyses of variance (ANOVA) revealed main effects for time (pretreatment, posttreatment) on the dependent measures of sibling knowledge, sibling adjustment, sibling connectedness, and sibling behavioral functioning. As displayed in Table 1, siblings' ability to accurately name, $F(1, 53) = 10.26, p < .01$, and explain, $F(1, 53) = 22.98, p < .01$, the child's disorder increased from pre- to posttreatment. Scores on the SPQ Negative Adjustment scale (sibling report) decreased from pre- to posttreatment, $F(1, 53) = 4.58, p < .05$, indicating a reduction in symptoms of negative adjustment. Results for the SPQ Negative Adjustment (parent report) were not significant, $F(1, 43) = 2.60, p < .11$. Both siblings', $F(1, 53) = 44.20, p < .01$, and parents', $F(1, 43) = 32.90, p < .01$, reports of sibling connectedness increased from pre- to posttreatment. Finally, there were decreases in internalizing, $F(1, 39) = 9.41, p < .01$, and externalizing, $F(1, 39) = 13.40, p < .01$, *T* scores on the CBCL from pre- to posttreatment, indicating statistically significant reductions in parent report of global behavior problems.

Diagnostic Differences. Repeated measures ANOVA were conducted to assess the effects of the type of the brother/sisters' disorder and time on all outcome

measures. These analyses compared siblings of children with a physical disability, autism spectrum disorder, mental retardation, medical disorder, or psychiatric disorder. For siblings' ability to explain the disorder, there was a main effect of the child's disorder, $F(4, 49) = 4.72, p < .01$, and an interaction between time and the child's disorder, $F(4, 49) = 4.72, p < .01$. Siblings of children with autism spectrum disorders, psychiatric disorders, and mental retardation provided less accurate explanations of the disorders, and their levels of accuracy increased more from pre- to posttreatment, in comparison to siblings of children with physical disabilities or medical disorders.

Gender Differences. Repeated measures ANOVAs were conducted to assess main effects of sibling gender and time on all outcome measures. For siblings' ability to name the disorder, there was a main effect of sibling gender, $F(1, 52) = 5.97, p < .05$, and an interaction effect, $F(1, 52) = 4.55, p < .05$, between time and sibling gender. Girls were more accurate in naming the disorder than boys; boys' accuracy in naming the disorder increased more than girls' from pre- to posttreatment.

Three-Month Follow-Up

Repeated measures ANOVAs were conducted to assess the main effects of time, with pairwise comparisons among the means for pre-, post-, and 3-months posttreatment, on the outcome measures completed by the 20 families who participated in the 3-month follow-up (see Table 1). There was a main effect of

time for siblings' ability to accurately explain the child's condition, $F(2, 18) = 3.60, p < .05$. The accuracy scores increased from pre- to posttreatment ($p < .05$) but decreased from posttreatment to 3-month follow-up ($p < .05$). As reported by siblings, $F(2, 18) = 9.20, p < .01$, and parents, $F(2, 14) = 7.39, p < .01$, sibling connectedness increased significantly from pre- to posttreatment ($p < .01$) and from pre- to 3-months posttreatment ($p < .01$). On the CBCL, there was a main effect of time for the internalizing, $F(2, 14) = 4.20, p < .05$, and externalizing, $F(2, 14) = 5.51, p < .05$, T scores. Externalizing T scores decreased at posttreatment ($p < .05$) and at 3 months posttreatment ($p < .05$). Internalizing T scores decreased significantly from pre- to posttreatment ($p < .05$) but not from pre- to 3 months posttreatment ($p < .09$).

Discussion

By intervening jointly with siblings and parents, the SibLink model emphasized the family as a primary context for sibling understanding and adjustment to a child's illness or disability. This introduces a shift from previous sibling group interventions that have targeted siblings only as individuals with needs for information and peer support (e.g., Lobato, 1990; Meyer & Vadasy, 1994). Compared to baseline, measures of sibling knowledge of the child's disorder and sibling connectedness increased, while sibling reports of negative adjustment to the disorder and parent reports of sibling behavioral problems decreased significantly after treatment for both boys and girls and across types of diagnostic conditions. There was no evidence that increasing siblings' knowledge and discussion of disability-related experiences was associated with any negative emotional or behavioral outcome, at least when these occurred within an atmosphere of parent support. It is possible that increasing information and exposure to disability-related topics might have a different effect on the emotional and behavioral functioning of siblings within families whose values and motivations are less consistent with these goals. Most parents in the sample (52.5%) reported that they had volunteered for the program because they wanted their well children to be able to meet and talk to peers with similar family circumstances. Thus, this sample may have been biased in favor of families who could support the program goals.

Overall, siblings who participated in the program

appeared representative of siblings of children with CI/DD described in the literature (Stoneman & Berman, 1993), insofar as mean scores for parents' reports of siblings' global behavioral functioning were not significantly elevated. The parent component of the program provided information and discussion regarding typical and atypical sibling behavior and relationships. It is possible that the reductions in parent-reported behavioral problems reflected changes in parent perspectives on sibling behavior, actual changes in sibling behavior, or a combination of both. While the decreases in CBCL T scores were statistically significant, the scores were well within normal limits both before and after treatment.

The SibLink program was designed to deal with sibling challenges that cut across types of diagnostic conditions. Siblings were grouped together without regard to the type of diagnosis of the child. While treatment effects were similarly positive across diagnostic conditions, there were some interesting main effects and interactions associated with diagnosis. Specifically, in comparison to siblings of children with physical disabilities or medical disorders, siblings of children with autism spectrum disorder, mental retardation, and psychiatric disorder expressed less knowledge of these conditions at pre-treatment and their knowledge increased more from pre- to posttreatment. We expect that the less visible, less specific, and perhaps more stigmatizing nature of these three diagnoses partially accounts for the lesser accuracy of siblings' knowledge prior to treatment.

The finding that results regarding negative adjustment to CI/DD differed as reported by siblings and parents on the SPQ raises questions regarding the psychometric properties of the instrument as well as the sensitivity of parents as informants regarding siblings' specific adjustment to CI/DD. In general, the little that is known about the concordance between parent and sibling reports of sibling adjustment to CI/DD suggests that parents and siblings often differ in their reports of sibling symptoms (Guite, Lobato, Kao, & Plante, 2002). These issues of sibling-parent discordance as well as the psychometric properties of the SPQ as a measure of sibling adjustment require further investigation.

Certain limitations of this study are important to highlight. Most important, there was no control group against which to compare the measured pre-post changes. Second, despite the emphasis on the family aspect of the intervention, this project was not designed to test the relative or synergistic effects

of the sibling and parent components. Finally, the demographic profile of this sample was skewed toward white, middle-class, two-parent families, which limits the generalizability of the findings. The results of this study, however, do provide support for future research utilizing randomized controls and a more diverse participant sample to evaluate the effects of integrated sibling-parent group interventions on sibling adaptation to chronic illness and developmental disability.

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