Brief Report: Family-Based Group Intervention for Young Siblings of Children with Chronic Illness and Developmental Disability

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Objective To evaluate the impact of a family-based group intervention for young siblings of children with chronic illness and developmental disability (CI/DD). Methods Forty-three healthy siblings (ages 4–7 years) of children with CI/DD and their parents participated in an intervention designed to address sibling challenges that cut across types of diagnostic conditions. The intervention consisted of six sessions of collateral and integrated sibling-parent groups. Measures of sibling knowledge, sibling sense of connectedness with other children in similar family circumstances, and sibling global functioning were collected before and after intervention. A subsample of 17 families completed a 3-month follow-up. Results Siblings’ knowledge of the child’s disorder and sibling connectedness increased significantly from pre- to posttreatment for both boys and girls, regardless of the nature of the brother or sister’s condition. Sibling perceptions of self-competence increased from pre- to posttreatment, whereas parent reports of sibling behavioral functioning remained within the normal range. Improvements in sibling knowledge and connectedness maintained at follow-up. Parent satisfaction with the program was high. Conclusions Results support more controlled evaluations of family-based intervention to improve young sibling adaptation to CI/DD.

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

Having a brother or sister with a chronic illness or developmental disability (CI/DD) is a risk factor for sibling adjustment problems (Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002). The issues surrounding sibling relationships change over time as children develop and the family responds to illness-related and other life experiences (Bluebond-Langner, 1996). There are few well-controlled investigations across age ranges of siblings; those that exist generally place younger children at higher risk for adjustment problems (Hastings, 2003).

Certain factors may increase vulnerability among young siblings (under 8 years of age). Their egocentrism may lead to greater misunderstanding of their brothers’ or sisters’ condition and its impact on the family (Lobato, 1993). Families of young siblings may be in the more disruptive phases of acute illness, diagnosis, and treatment, which are associated with sibling distress (Craft, & Craft, 1989). Finally, parents may be particularly confused about how and when to share information about the child’s condition with young siblings (Lobato, Kao, Engel, & Plante, 2000).

We recently reported on a family-based group intervention (“SibLink”) that improved the understanding and adjustment of siblings (ages 8–13 years) of children with CI/DD (Lobato & Kao, 2002). Because young siblings have relatively less access to information and support independent of their parents, it is especially important that interventions for them be family based. This article presents results of the preliminary evaluation of a downward extension of SibLink on young siblings’ knowledge of their brother or sister’s condition, sense of connectedness with others in similar circumstances, and global functioning.

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Method
Recruitment
SibLink was offered as an outpatient service at a north-east urban children's hospital. Families responded to flyers and informational meetings at hospital clinics and community agencies serving children with CI/DD. Families whose children were in the end stage of illness or who had been diagnosed less than 6 months before the study were excluded. Parent consent was obtained before participation. The study had approval of the hospital's Institutional Review Board.

Participants
The sample consisted of 43 well siblings (17 boys, 26 girls) and their 40 parents (in three cases, two siblings from the same family participated). Siblings ranged in age from 4 to 7 years (M = 5.7 years) and 51% of the siblings were older than the child with CI/DD. All siblings attended a school program; 54% were in preschool or kindergarten and 46% were in first or second grade.

The children with CI/DD (25 boys, 15 girls) were 1–19 years old (M = 6.1 years) and carried the following primary diagnoses: autism spectrum disorders including Asperger's disorder (35%), mental retardation (25%), physical disabilities such as cerebral palsy (23%), medical disorders such as cancer (14%), or dual psychiatric and learning disorders such as Tourette’s (3%). The mean length of time since their diagnosis was 4 years.

Most families were Caucasian (100%) and consisted of two parents (91%) and two to three children (92%). The mean age of mothers was 34 years and of fathers was 32 years. In terms of socioeconomic status (SES), 72% of the families were at a technical or professional level and had a median annual income of $40,000-46,000.

Evaluation Procedures
Pre- and Posttreatment
Separate parent and sibling evaluations were completed within 2 weeks of the first group meeting. Questions were read aloud to siblings; parents completed written questionnaires independently. Posttreatment evaluation occurred within 2 weeks of the final group session. The same parent (98% mothers) completed the pre- and posttreatment questionnaires.

Three-Month Follow-up
In the last 2 years of the project, we received private foundation funding to conduct an additional evaluation 3-months after treatment. Of the 21 families who participated during this time period, 17 families volunteered to complete the extra post-3-month evaluation and were compensated $20.00. There were no significant demographic differences between the 17 families who completed the 3-month follow-up, the 4 families who declined the follow-up, or the rest of the sample.

Evaluation Measures
Sibling Knowledge of CI/DD
Siblings participated in a structured interview to assess knowledge of their brother/sister's disorder (Lobato & Kao, 2002). First, siblings were asked to name the child’s disorder (i.e., “Tell me the name of your brother/sister's problem”). Responses were coded on a scale of 1–4, ranging from not knowing the name to stating a specific and accurate term. Siblings were then asked to explain the child's disorder (i.e., “What does it mean to have <CI/DD name>?”). Follow-up questions elicited the child's understanding of characteristics such as core symptoms and treatment. Responses were coded on a scale of 1–5, ranging from no understanding to accurate understanding. To assess interrater reliability, two coders blind to participant identity and time of evaluation independently rated 10% of the sibling responses. Chance-corrected agreement was 100% for both name and explanation of the disorder.

Sibling Connectedness
Two questions assessed sibling sense of connectedness with other children in similar family circumstances. On a 4-point Likert scale ranging from 1 (“never”) to 4 (“a lot”), siblings and parents were asked whether siblings had “talked to” and “knew” other children with a brother/sister with problems. At pretreatment, these two items were correlated per parent report (r = 0.52, p < .01) but not per sibling report (r = 0.13, p < .40). Thus, individual item scores were used in analyses.

Sibling Global Functioning
Siblings completed the Pictorial Scale of Perceived Competence and Social Acceptance for Young Children (Harter & Pike, 1983) at pre- and posttreatment to assess their perception of their own cognitive competence, physical competence, peer acceptance, and maternal acceptance. The Pictorial Scale has acceptable internal consistency when used with preschoolers to second graders of middle class backgrounds. The items are rated on a scale of 1–4, with higher scores indicating greater perceived competence and acceptance.

The Child Behavior Checklist Ages 4–18 (CBCL; Achenbach, 1991) was administered before, after, and
3 months after treatment to obtain a normative measure of global behavioral functioning and to monitor for negative side effects of group participation.

**Participant Satisfaction**
At posttreatment, parents anonymously rated their overall satisfaction with the intervention on a scale of 1 ("not at all satisfied") to 5 ("very satisfied").

**Treatment**
The overall model of intervention for young siblings paralleled the program for older siblings (Lobato & Kao, 2002). The program was designed to address sibling challenges that cut across types of diagnostic conditions. Siblings and parents participated in six 90-minute sessions of collateral and integrated sibling-parent groups. Activities were detailed in separate parent and sibling group treatment manuals.

Nine groups averaging five siblings each were led by two doctoral level psychology trainees. Siblings were grouped together without regard to the diagnosis of the child with CI/DD. The collateral sibling group activities alternated between explicitly focused “main events” and other more social-recreational activities that implicitly addressed sibling connectedness. Two sessions targeted improving sibling knowledge and family discussions about the child's condition. Two sessions targeted identifying and managing sibling emotions with problem solving around challenging situations typical for young siblings and one session focused on identifying siblings' strengths and balancing siblings' individual needs within the family. The final session provided a review and graduation ceremony.

Collateral parent groups consisted of five to six parents led by a licensed clinical psychologist. The format of the parent group “main events” involved a mix of didactic presentation, group discussions, and an open forum with an adult sibling. Discussion topics paralleled those of the sibling group and emphasized issues related to within-family functioning, enhancing communication about CI/DD with young children, and understanding how the unique developmental characteristics of young children affect sibling knowledge of and coping with CI/DD.

Integrated sibling and parent groups also were conducted to enhance mutual understanding and perspective taking. Siblings created a videotape about their experiences as a brother or sister that parents reviewed. Sibling and parent groups joined for portions of four of the sessions to read books about siblings and illness or disability together, to engage in interactive exercises, and to participate in a graduation.

**Results**
All enrolled families completed treatment. Attendance rates were high; 86% of families attended all sessions. In two families, fathers only attended all sessions and in 38 families, mothers attended all sessions. Of these 38 families, three fathers also attended all sessions and four fathers attended one or two sessions. Complete pre–post sibling data existed for all 43 siblings; complete pre–post parent data existed for 40 (93%) of the 43 siblings (three parents did not complete post questionnaires). There were no significant demographic differences between the families with and without parent pre–post data. Parent ratings of satisfaction with the program were high (4.7 out of 5). Parents most commonly reported that the connection with others in similar family circumstances was what they liked most about the program for their children (67%) and themselves (71%).

**Pre–Post Evaluation**
Repeated measures analyses of variance (ANOVAs) were conducted to assess the main effects of time (pre- or posttreatment) on the dependent measures of sibling knowledge, connectedness, and global functioning. As displayed in Table I, siblings' ability to accurately name and explain the child's disorder increased from pre- to posttreatment. Both siblings' and parents' reports of siblings knowing and talking to other children increased from pre- to posttreatment.

On the Pictorial Scale, siblings' cognitive competence and physical competence scores increased from pre- to posttreatment. Results for the peer acceptance and maternal acceptance scores were not significant. Results for the CBCL total score were not significant.

**Diagnostic and Gender Differences**
Repeated measures ANOVA were conducted to assess the effects of type of disorder and sibling gender and time (pre- or posttreatment) on all outcome measures. There were no significant effects of type of disorder or sibling gender.

**Three-Month Follow-up**
Repeated measures ANOVAs were conducted to assess the main effects of time (before, after, or 3 months after treatment) with post hoc pairwise comparisons on the outcome measures completed by the 17 families who participated in the follow-up. As displayed in Table I, parents' report of siblings talking to other children increased significantly from pre- to posttreatment and from pre- to 3-months posttreatment. Parents' report of
siblings knowing other children also increased from pre-
to posttreatment. Although power was adequate for the
large effect sizes of these two variables (ES = .55–.56),
power was low to detect medium effect sizes. Increases
in siblings’ ability to name the disorder (ES = .24) and
their report of knowing other children (ES=.33)
approached significance.

Discussion
This downward extension of the SibLink model empha-
sized the family as the primary context for siblings’
adaptation to a child’s illness or disability. Compared to
baseline, young sibling knowledge of the child’s disorder
and sense of connectedness increased, whereas parent
reports of sibling behavioral functioning remained stable
and within the normal range. Increasing siblings’ knowl-
edge and discussion of illness-related experiences was
not associated with any negative emotional or behavioral
outcome. In fact, siblings’ perceptions of their own com-
petence increased significantly from pre- to posttreatment.
The intervention was very well received, as
evidenced by parents’ high satisfaction, excellent attend-
dance, and 100% program completion rates. Because
there were no monetary incentives provided for partici-
pation in the program, these results suggest that our
family-based intervention addressed a need important to
the families.
The current design does not allow us to assess
which aspects of the intervention were associated with
the observed changes in sibling knowledge, connected-
ness, and perception of competence. However, we have
given considerable thought to the mechanisms for
change in family-based interventions such as SibLink
that are questions for future research. We hypothesize
that explicit and implicit characteristics of the interven-
tion contribute to changes in individual and family pro-
cesses. For example, increases in sibling knowledge may
be directly associated with curriculum content but may
also be reinforced by parents who are better able to com-
municate with the sibling about CI/DD. The increases in
the siblings’ perceptions of their own cognitive and
physical competence may be related to increased atten-
tion to positive sibling qualities during group and from
parents, and, perhaps, to siblings beginning to differenti-
ate their own health and abilities from those of their
brother or sister as they learn more about CI/DD.

Certain limitations of this pilot are important to
highlight. The intervention was not compared to a con-
trol group and the assessment battery lacked a measure of
the young siblings’ specific adjustment to CI/DD. The
demographic profile of the current sample was skewed
toward white, middle-class families, and the global func-
tioning of the young siblings was within normal limits.
The results may not generalize to families from more
diverse backgrounds or to siblings with preexisting
behavioral problems.

The results of this project are encouraging of future
research utilizing a more diverse participant sample and ran-
domized control groups. Although preliminary, the results
support continued development and testing of family-
based, early interventions to promote understanding and
psychological adjustment among young siblings of children
with chronic illnesses and developmental disabilities.

Table I. Mean Scores on Outcome Measures Completed Before, After, and 3 Months After Treatment

<table>
<thead>
<tr>
<th>Measures</th>
<th>Full sample (n = 43)</th>
<th>Follow-up sample (n = 17)</th>
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<tbody>
<tr>
<td></td>
<td>Pretreatment</td>
<td>Posttreatment</td>
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<tr>
<td></td>
<td>M ± SD</td>
<td>M ± SD</td>
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<td></td>
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<tr>
<td>Sibling knowledge:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Name</td>
<td>2.5 ± 1.19</td>
<td>3.5 ± 0.99**</td>
</tr>
<tr>
<td>Explanation:</td>
<td>3.0 ± 1.05</td>
<td>3.7 ± 0.87**</td>
</tr>
<tr>
<td>Sibling connectedness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Know other kids (sibling)</td>
<td>1.9 ± 1.03</td>
<td>2.6 ± 1.30**</td>
</tr>
<tr>
<td>Talk to other kids (sibling)</td>
<td>1.7 ± 1.05</td>
<td>2.2 ± 1.24*</td>
</tr>
<tr>
<td>Know other kids (parent)</td>
<td>2.0 ± .89</td>
<td>2.8 ± .80**</td>
</tr>
<tr>
<td>Talk to other kids (parent)</td>
<td>1.6 ± .87</td>
<td>2.8 ± .84**</td>
</tr>
<tr>
<td>Child Behavior Checklist: Total T</td>
<td>52 ± 10.45</td>
<td>52 ± 11.42</td>
</tr>
<tr>
<td>Pictorial Scale: Cognitive competence</td>
<td>3.4 ± .044</td>
<td>3.7 ± .028**</td>
</tr>
<tr>
<td>Physical competence</td>
<td>3.4 ± .37</td>
<td>3.6 ± .30**</td>
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<tr>
<td>Peer acceptance</td>
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<td>3.0 ± .70</td>
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<tr>
<td>Maternal acceptance</td>
<td>2.8 ± .59</td>
<td>2.9 ± .54</td>
</tr>
</tbody>
</table>

*p < .05, **p < .01.
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References


