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The use of the Impact on Sibling Scale with families of children with chronic illness and developmental disability

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Abstract

Objective: This study evaluated the Impact on Sibling scale, a six-item measure of parents' perception of the effects of a child's illness on healthy siblings.

Methods: Participants were 122 parents of a child with chronic illness, developmental disability, or autism spectrum disorder, and a well sibling 4 to 13 years. Parents completed the Impact on Sibling scale and the Child Behavior Checklist about the sibling, and completed the revised Impact on Family Scale and the Brief Symptom Inventory about themselves.

Results: The Impact on Sibling score was correlated with measures of sibling, parent, and family functioning. The internal consistency of the Impact on Sibling scale was higher for families with children with chronic illness compared to the other two diagnostic groups.

Conclusion: The Impact on Sibling scale is a brief set of items that can help identify siblings who are negatively affected by a brother/sister's illness. Findings support further research on the Impact on Sibling scale, particularly with families of children with chronic illnesses.

Keywords

siblings; family; childhood chronic illness

Introduction

The Impact on Family Scale (IOF; Stein & Reissman, 1980) was developed as a parent report measure of the effects of a child's medical condition on family life. The authors also developed an optional six-item Impact on Sibling scale about parents' perception of the effects of a child's illness on well siblings who were at least four years old (IOS; Stein &

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Key Messages

- A child's chronic illness or disability affects all family members.
- Family-centered assessments should include evaluation of well siblings' functioning. However, there are few measures that focus on siblings' adjustment to their brother/sister's disorder.
- Evidence is provided about the reliability and validity of The Impact on Sibling scale, a parent report scale about the effects of a child's illness on siblings. Findings indicate that the Impact on Sibling scale may be particularly useful with families of a child with a chronic medical condition.

Jessop, 1985). The item content reflect siblings' emotional and behavioral reactions to the illness, the impact of the illness on siblings' school performance, and parental concerns about siblings' health and about their own ability to attend to the needs of all of their children.

There has been little published research in which the Impact on Sibling scale has been used, and the scale has not been the focus of the studies. Wright, Boschen, and Jutai (2005) reported Impact on Sibling scale scores for 6 families of children with cerebral palsy. A subset of 26 parents completed the Impact on Sibling scale in a study of families of children with chronic illnesses and developmental disabilities (Guite, Lobato, Kao, & Plante, 2004). Parents who reported more negative adjustment for siblings than the siblings endorsed also reported more negative impact of the illness on the Impact on Sibling scale.

The Impact on Family Scale has been widely used and was revised in 2003 (Stein & Jessop, 2003). The revised IOF Scale consists of 15 items reflecting the impact of chronic childhood illness on social and family functioning. Williams and colleagues (Williams et al., 2006) used the revised IOF scale and found that greater impact of the child's illness/disability on the family was associated with behavior problems in a well sibling. These results were consistent with meta-analyses (Rossiter & Sharpe, 2001; Sharpe & Rossiter, 2002) indicating that siblings are at risk for psychological adjustment problems, and highlight the need to include siblings when assessing families with a child with chronic illness and developmental disabilities (CI/DD). There are few measures that focus on sibling's adjustment to illness. The purpose of this study was to evaluate the psychometric properties and the relationship of the Impact on Sibling scale to aspects of sibling and family functioning with families of children with medical, developmental, and autistic disorders.

Method

Participants

Participants were recruited via brochures, informational meetings, and contact with research assistants who attended hospital clinics and local agencies serving children with chronic illness and developmental disability. Parent consent was obtained prior to participation in several studies of sibling adaptation and treatment which had approval of the hospital's institutional review board.

The sample consisted of 122 parents (98% mothers, 2% fathers). The majority of families had two parents (88.5 %) with 2 (52%) or 3 (35%) children and an annual income of \$40,000 or more (73%). Families self identified as Caucasian (85%), Latino (10%), or other ethnic/racial group (5%). Parents completed measures about their child with CI/DD ages 1 to 16 years old and about a healthy sibling ages 4 to 13 years. If families had more than one sibling in the 4 to 13 year age range, parents completed measures about the sibling closest in age to the child with CI/DD. Characteristics of the parents, siblings, and children with CI/DD are presented in Table 1. There were 36 families with a child with a chronic illness such as a metabolic disorder. There were 36 families with a child with a developmental disability, either developmental delay or mental retardation. Fifty families had a child with a diagnosis within the autism spectrum of Autistic Disorder or Pervasive Developmental Disorder, Not Otherwise Specified.

Measures

Parents completed the revised Impact on Family (IOF) scale (Stein & Jessop, 2003) and the Impact on Sibling scale (Stein & Jessop, 1985). On both measures, items were rated on a 1 to 4 point scale with higher scores reflecting more negative impact of the child's condition. The IOF scale has 15 items with a score range of 15 to 60. Alpha coefficients for the IOF

scale ranged from .87 to .90 (Stein & Jessop, 2003). The Impact on Sibling scale has 6 items with a score range of 6 to 24. Stein and Jessop (1985) reported an alpha coefficient of .72 for the Impact on Sibling scale.

Parents completed The Brief Symptom Inventory (BSI; Derogatis, 1993) as a self-report measure of their overall psychological symptoms and distress. Symptoms were rated on a five-point scale of distress and higher scores reflect more symptoms. The Global Severity Index (GSI) T-score was used in the analyses. The BSI has demonstrated reliability and validity with a test-retest reliability coefficient of .90 for the GSI (Derogatis, 1993).

Parents completed the Child Behavior Checklist/4 to 18 (CBCL; Achenbach, 1991) as a measure of siblings' global behavioral functioning. Data collection began before the 2001 revision of the CBCL, so the 1991 CBCL was administered to all participants to maintain data continuity. Behavior problems were rated on a scale from 0 (not true) to 2 (very true). The CBCL Total Behavior Problems T-score, an indication of overall emotional and behavioral problems, was used in the analyses. The CBCL is an established measure with documented reliability and validity. Achenbach (1991) reported an alpha coefficient of .96 for the CBCL Total Behavior Problems scale.

Procedure

Parents provided information about the family demographics and the child's diagnosis and completed the questionnaires. All parents ($N = 122$) completed the Impact on Sibling scale and the CBCL, 119 parents completed the IOF scale, and 111 parents completed the BSI.

Results

Total Sample

For the total sample, internal consistency was $\alpha = .90$ for the IOF scale. For the Impact on Sibling scale, the α was .73 and the mean inter-item correlation was .32 with correlations ranging from $r = .05$ to $r = .59$. The Impact on Sibling score was correlated with the IOF Score ($r = .68, p < .01$), the CBCL Total T-score ($r = .40, p < .01$), and the BSI GSI T-score ($r = .41, p < .01$). The IOF score was correlated with the CBCL Total T-score ($r = .25, p < .01$) and BSI GSI T-score ($r = .40, p < .01$). The CBCL Total and BSI GSI T-scores were also correlated ($r = .44, p < .01$). The Impact on Sibling score was not significantly related to demographic characteristics of the sibling, child, or family.

The mean CBCL Total T-score of 52.74 ($SD = 11.61$) for the sample was within normal limits. Using the cutoff of T-scores ≥ 67 (Achenbach, 1991), 18 siblings (15%) had a CBCL Total T-score in the clinical range. The 18 parents who reported a clinically elevated CBCL Total T-score reported significantly higher Impact on Sibling scores ($M = 15.67, SD = 3.07$) than the other 104 parents ($M = 12.81, SD = 3.35$), $F(1, 120) = 11.47, p < .01$.

Three Diagnostic Groups

Internal consistency of the Impact on Sibling scale was highest for the chronic illness group ($\alpha = .83$), compared to the developmental disability ($\alpha = .70$) and the autism spectrum disorders ($\alpha = .64$) groups. The mean inter-item correlation was also higher for the chronic illness group (.45) compared to the developmental disability (.30) and autism spectrum disorders (.24) groups. Internal consistency for the IOF score was comparable for the chronic illness ($\alpha = .91$), developmental disability ($\alpha = .92$), and autism spectrum disorders ($\alpha = .86$) groups.

One-way analyses of variance and chi square analyses were used to compare the three diagnostic groups. There were no significant differences in demographic characteristics of the siblings and parents of the three groups. There were group differences on the mean IOF score, $F(2, 116) = 3.30, p < .05$ (See Table 2). Post hoc analyses indicated that parents of a child with autism spectrum disorders reported higher IOF scores than parents of a child with developmental disability ($p < .05$). The mean IOF score for the chronic illness group fell in between the other two groups and did not differ significantly. The groups did not differ significantly on the BSI, CBCL, or Impact on Sibling mean scores. There was a difference for one Impact on Sibling item. Parents of children with chronic illness reported higher mean scores for worrying about their other children's health ($M = 2.7, SD = .88$), than parents of a child with developmental disability ($M = 2.1, SD = .98$) and parents of a child with autism spectrum disorders ($M = 2.4, SD = .93$), $F(2, 119) = 3.90, p < .05$. There were no significant group differences on the mean scores of the other five Impact on Sibling scale items. The percentage of siblings with a clinically elevated CBCL Total T-score did not differ between the three groups.

Within each diagnostic group, the Impact on Sibling score was correlated with the IOF score, the CBCL Total T-score, and the BSI GSI T-score (see Table 3). The IOF score was correlated with the BSI GSI T-score for the developmental disability and autism spectrum disorders groups, and with the CBCL Total T-score for the developmental disability group. Within all diagnostic groups, the CBCL Total and BSI GSI T-scores were correlated.

Discussion

This study evaluated the Impact on Sibling scale, a measure of parents' perception of the effects of a child's illness on well siblings. Greater impact of the illness on siblings was associated with parent report of sibling behavior problems, parental distress, and overall impact of the child's illness on the family. Consistent with Stein and Jessop (2003), the internal consistency of the Impact on Sibling scale was lower compared to the Impact on Family score. The internal consistency was higher for families with a child with a chronic illness, which may reflect the scale content. The Impact on Sibling scale was developed with families of children with medical conditions and the items may have been more salient for parents with a medically involved child. In our sample, parents of a child with chronic illness were more likely to report worrying about the health of their other children. Parents of a child with autism reported the highest mean Impact on Family score. This group also had the lowest internal consistency for the Impact on Sibling scale. Children with autism spectrum disorder typically have a combination of developmental, social, and behavioral symptoms. The Impact on Sibling scale may not capture the many challenges that a child with autism presents to their siblings.

There were limitations in the current study. Participants were self selected and included parents only, primarily mothers. Research indicates that parents' reports are more negative than siblings' report of sibling psychological functioning (Guite et al., 2004; Sharpe & Rossiter, 2002). Future studies should include other informants such as siblings, fathers, and teachers, and assess other outcomes such as school performance, to provide more information about the utility of the Impact on Sibling scale and its relationship to aspects of sibling functioning.

Family-centered evaluations should include measures of sibling functioning. The Impact on Sibling scale is a brief set of items that can be easily incorporated into family assessments in clinical and research settings. While a six-item scale does not capture the multiple psychosocial consequences of a child's illness/disability on sibling relationships, the scale does provide parents with an opportunity to report concerns about siblings and has the

potential to identify siblings who are negatively affected by a brother/sister's illness and may require further assessment. Sibling adjustment problems contribute to the stressors that families experience when raising a child with a chronic illness or disability. These families would benefit from interventions to help them cope with the multiple demands of having a child with special needs. Our findings expand upon the database about the Impact on Sibling scale, and support further research on the measure particularly with families with a child with a chronic illness.

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Table 1

Demographic Characteristics of the Participants by Child's Diagnosis

	Chronic Illness (n = 36)	Developmental Disability (n = 36)	Autism Spectrum Disorder (n = 50)
<u>Parent</u>			
Mother's age in years (M, SD)	36.37 (5.40)	37.86 (6.20)	37.98 (5.53)
Ethnicity, % Caucasian	86%	92%	80%
<u>Sibling</u>			
Age in years (M, SD)	8.5 (2.12)	7.6 (2.02)	7.8 (2.20)
Sex, % male	53 %	50%	68%
% older than the child with CI/DD	53%	58%	68%
<u>Child with Disability</u>			
Age in years (M, SD)	7.4 (3.92)	7.3 (3.63)	7.0 (3.21)
Sex, % male	50%	58%	86%
Time since diagnosis in years (M, SD)	4.1 (3.51)	6.1 (4.08)	4.0 (2.89)

Table 2

Mean Scores on Measures for the Three Diagnostic Groups

	Chronic Illness (n = 36) Mean SD	Developmental Disability (n = 36) Mean SD	Autism Spectrum Disorder (n = 50) Mean SD
Impact on Sibling Scale	13.47 (3.97)	12.67 (3.51)	13.46 (3.00)
Impact on Family Scale	36.56 (10.34)	33.21 (10.12)	38.57 (7.95) *
CBCL Total T-score	53.08 (11.36)	53.31 (10.82)	52.08 (12.50)
BSI GSI T-score	53.97 (11.36)	54.56 (9.93)	54.29 (10.86)

Note.

CBCL = Child Behavior Checklist. BSI GSI = Brief Symptom Inventory Global Severity Index.

*
 $p < .05$.

Table 3

Correlations between the Measures for the Three Diagnostic Groups

	IOF Scale	CBCL Total T-score	BSI GSI T-score
Chronic Illness (n = 36)			
IOS Scale	.72 **	.47 **	.43 *
IOF Scale		.27	.33
CBCL Total T-score			.46 **
Developmental Disability (n = 36)			
IOS Scale	.78 **	.40 *	.41 *
IOF Scale		.37 *	.51 **
CBCL Total T-score			.45 **
Autism Spectrum Disorder (n = 50)			
IOS Scale	.54 **	.39 **	.43 **
IOF Scale		.22	.43 **
CBCL Total T-score			.43 **

Note.

IOS = Impact on Sibling. IOF = Impact on Family. CBCL = Child Behavior Checklist. BSI GSI = Brief Symptom Inventory Global Severity Index.

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