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Family Variables Associated With Well-Being in Siblings of Children With Down Syndrome

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The purpose of this research was to examine relationships among family demands, family resources, family problem-solving communication, family coping, and sibling well-being in 41 families of children with Down syndrome. The guiding framework for this research was the resiliency model of family stress, adjustment, and adaptation. Mailed questionnaires were completed by mothers and siblings closest in age to the children with Down syndrome. Results indicate that, as a group, the siblings in this study had favorable self-concepts. In addition, maternal reports typically indicated that these siblings were socially competent, with a low incidence of behavior problems. All four family variables were significantly associated with at least one of the indicators of sibling well-being. This research adds a critical piece, the sibling piece, to a fascinating puzzle concerning how families respond to the multiple challenges associated with raising a child with Down syndrome.

Down syndrome, the most common chromosomal disorder associated with mental retardation, affects not only the well-being of the affected individual but also the well-being of other family members (Crnic, 1990; Fisman & Wolf, 1991; Hornby, 1995). To date, much of the research concerning well-being in families of children with Down syndrome has been directed at documenting how parents respond to the birth and rearing of a child with a chronic condition (e.g., Cahill &

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Glidden, 1996; Cheng & Tang, 1995; Herbert & Carpenter, 1994; Padelia, 1998; Rodrigue, Morgan, & Geffken, 1992; Scott, Atkinson, Minton, & Bowman, 1997; Sloper, Knussen, Turner, & Cunningham, 1991; Van Riper, 1999a; Van Riper, Ryff, & Pridham, 1992).

Despite increasing evidence that the well-being of nondisabled children may be profoundly affected by the experience of living in a family that includes a child with a chronic condition (Dyson, 1989; Faux, 1993; Lobato, 1983; Senapati & Hayes, 1988; Simeonsson & McHale, 1981; Stoneman & Berman, 1993), relatively few researchers have assessed sibling well-being in families that include a child with Down syndrome (Carr, 1988; Gamble & McHale, 1989; Gath, 1972, 1973, 1974, 1990; Gath & Gumley, 1987; Lobato, Barbour, Hall, & Miller, 1987; McHale & Gamble, 1989). Moreover, much of the existing research has focused on negative indicators of sibling well-being (e.g., depression, anxiety, and behavior problems), rather than positive indicators (e.g., social competence, self-concept). In addition, the findings that are available are contradictory and inconclusive (Boyce & Barnett, 1993). It remains unclear why some siblings of children with Down syndrome are resilient and thrive, whereas others suffer negative consequences.

PURPOSE AND SIGNIFICANCE OF THIS RESEARCH

The purpose of this research was to examine relationships among family demands, family resources, family problem-solving communication, family coping, and sibling well-being in families that include a child with Down syndrome. The significance of this research relates to several issues. First, considering that approximately 350,000 families in the United States are affected by Down syndrome, and the vast majority of these families include one or more nondisabled children (National Down Syndrome Society, 1999), sheer numbers alone make siblings of children with Down syndrome a significant population to be studied. Second, siblings spend more time together than any other family subsystem (Bank, 1981; Bank & Kahn, 1975; Kahn & Lewis, 1988). Because of this, siblings exert a powerful influence on each other. It has been suggested that when one sibling has a chronic condition, this influence becomes even stronger, especially if the nondisabled sibling takes on additional caretaking responsibilities (Gallo, 1988; Gath, 1974; McHale & Gamble, 1989; Siemon, 1984). Third, given that the average life expectancy for individuals

with Down syndrome has been extended from 9 to 55 years (Lott & McCoy, 1992) and the vast majority of these individuals live with or under the supervision of family members throughout their lives (Seltzer & Krauss, 1993), the need to understand how children respond to the experience of living in a family that includes a child with Down syndrome is even greater today than it was in prior decades.

GUIDING FRAMEWORK

The guiding framework for this research was the resiliency model of family stress, adjustment, and adaptation (McCubbin & McCubbin, 1993). The Resiliency Model helps to explain why some families adapt and become stronger in the face of stressful circumstances, whereas others remain vulnerable, and some deteriorate. Family adaptation, the central concept of the Resiliency Model, is defined as the outcome of family efforts to bring a new level of balance, harmony, coherence, and functioning to a stressful or crisis family situation. For families that include a child with Down syndrome, successful family adaptation (bonadaptation) occurs when the family is able to achieve a balance between meeting the needs of the child with Down syndrome, the needs of the family as a whole, and the needs of other family members. If the family is not able to achieve this balance, unsuccessful family adaptation (maladaptation) occurs. High levels of individual and family well-being suggest successful family adaptation, whereas low levels of individual and family well-being suggest unsuccessful family adaptation.

According to the resiliency model, two children that appear to be undergoing similar experiences (e.g., growing up with a sibling who has Down syndrome) may respond very differently, depending on a series of interacting components that shape the family process and outcomes of adaptation (see Figure 1). In this study, the focus was limited to three of these components (i.e., family demands, family resources, and family problem solving and coping).

LITERATURE REVIEW

To date, there have been no published reports of research in which the Resiliency Model was used to examine sibling well-being in families of children with Down syndrome. However, there have been

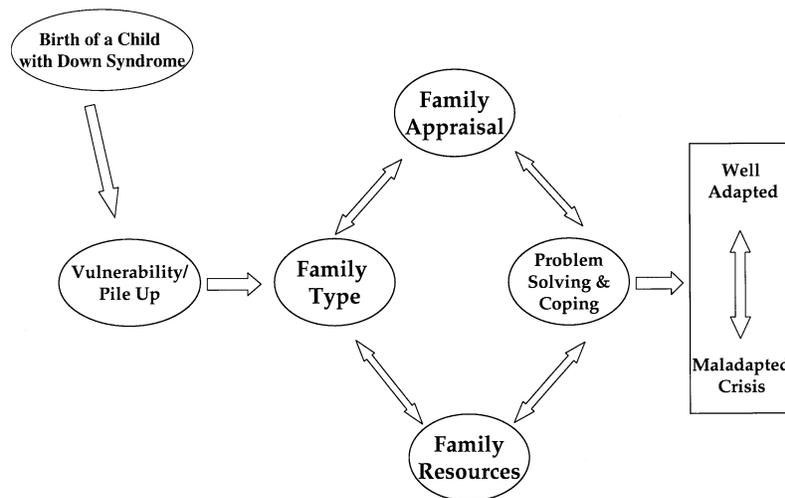


Figure 1: Resiliency Model of Family Stress, Adjustment, and Adaptation (Adapted from McCubbin & McCubbin, 1993)

reports of findings concerning families of children with Down syndrome and other chronic conditions that relate to sibling well-being and the three components of the Resiliency Model examined in this research.

Family Demands

There is overwhelming evidence that families of children with Down syndrome experience higher levels of stress than families with nondisabled children (Cunningham, 1996; Dumas, Wolf, Fisman, & Culligan, 1991; Padeliadu, 1998; Sander & Morgan, 1997). Families of children with Down syndrome are subject not only to the pileup of demands (e.g., stresses, strains, and transitions) faced by families with typically developing children but also to the unique responsibilities and challenges associated with raising a child with Down syndrome. Parents of children with Down syndrome have increased time demands (Barnett & Boyce, 1995; Padeliadu, 1998). They devote more of their time to child care and educational activities and less of their time to social activities than do parents of nondisabled children (Barnett & Boyce, 1995). When the pileup of demands on or within the

family unit is high, meeting the needs of the child with Down syndrome may take precedence over meeting the needs of other family members. Siblings of children with Down syndrome may experience a decrease in their self-concept (i.e., the way they feel about themselves) or an increase in behavior problems, especially if they feel neglected or imposed upon due to increased family demands.

Family Resources

Family resources play an important role in family adaptation to the ongoing challenges associated with raising a child with a chronic condition (Patterson, 1995). In a study by Dyson (1997), there was a significant negative association between family psychological resources (e.g., family emphasis on personal growth, family cohesion, family support) and parental stress in families that include a child with a disability. Findings from a large longitudinal study by Cunningham (1996) and colleagues revealed a significant positive association between utilitarian family resources (e.g., finances, housing, employment) and well-being in families of children with Down syndrome. Families with more resources have a better chance of managing stress and restoring balance in their lives than families with limited resources (McCubbin & McCubbin, 1993). Therefore, it is likely that there will be a positive association between family resources and sibling well-being in families of children with Down syndrome.

Family Problem Solving and Coping

Family adaptation to the challenges associated with raising a child with Down syndrome will depend, in part, on the depth and range of the family's repertoire of problem-solving and coping strategies (McCubbin & McCubbin, 1993). Families who use numerous strategies to problem solve and cope will adapt more successfully than will families who use a limited number of strategies, especially if these are passive strategies. In the longitudinal study by Cunningham (1996) and colleagues, the strongest coping strategy to emerge for parents of children with Down syndrome was wishful thinking, a passive strategy. Use of this strategy to cope with problems concerning the child with Down syndrome was negatively associated with measures of individual and family well-being.

Family adaptation may also vary depending on the type of communication families use to problem solve (McCubbin, Thompson, &

McCubbin, 1996). Families with an affirming style of problem-solving communication (one that conveys support and caring and exerts a calming influence) adapt more successfully to stressful situations than families with an incendiary style of problem-solving communication (one that is inflammatory in nature and tends to exacerbate a stressful situation). Sibling well-being is likely to be higher in families that use numerous strategies to problem solve and cope. In addition, there is likely to be a positive association between an affirming style of problem-solving communication and sibling well-being.

Sibling Well-Being

As noted previously, relatively few researchers have assessed sibling well-being in families of children with Down syndrome. In addition, much of the existing research has focused on negative indicators of sibling well-being, and the findings that are available are contradictory and inconclusive. For example, in a longitudinal study conducted by Carr (1988), siblings of children with Down syndrome were reported to have fewer behavioral problems than comparison siblings. Gath and Gumley (1987) found no difference in behavioral problems between siblings of children with Down syndrome and comparison siblings. In a study by McHale and Gamble (1989), siblings of children with disabilities (including Down syndrome) reported higher depression, higher anxiety, and lower perceived competence than comparison siblings. Lobato et al. (1987) found that brothers of children with disabilities (including Down syndrome) had significantly higher depression and aggression scores than did sisters of children with disabilities or siblings in the comparison group. Sisters of children with disabilities had higher aggression scores than comparison sisters. No difference was found between the perceived competence of siblings of children with disabilities and comparison siblings.

HYPOTHESES

Existing findings concerning sibling well-being in families of children with Down syndrome are contradictory and inconclusive. In addition, relatively little is known about relationships among family variables and sibling well-being in these families. Therefore, in this study a family framework, the Resiliency Model, was used to explore

relationships among family demands, family resources, family problem-solving communication, family coping, and sibling well-being. Positive associations were predicted between three of the family variables (family resources, family problem-solving communication, and family coping) and the positive indicators of sibling well-being (i.e., social competence, self-concept). A negative association was predicted between family demands and the positive indicators of sibling well-being. For behavior problems, a negative indicator of sibling well-being, the predictions were reversed.

METHOD

Design

A descriptive correlational design was used. This study was part of a larger effort to explore the sibling experience in families of children with Down syndrome (Van Riper, 1999b).

Sample

The sample for this study was a volunteer sample of 41 families of children with Down syndrome. As noted above, these families participated in a larger study concerning the sibling experience in families of children with Down syndrome ($n = 86$ families). The definition of family used in the larger study was "the family is who they say they are" (Wright & Leahey, 1994, p. 40). Families were recruited from Down syndrome support groups in Indiana ($n = 2$), Pennsylvania ($n = 2$), and Ohio ($n = 3$); from study family referrals; and through a mailing sent to families who had participated in previous research by this investigator. This report will focus on data from the 41 families in which both the mother and the sibling closest in age to the child with Down syndrome returned completed questionnaires.

Demographic characteristics of the sample are shown in Table 1. In general, the majority of the families were White (93%), two parent (95%), and middle class (35% had family incomes between \$25,000 and \$55,000) to upper class (54% had family incomes greater than \$55,000). The average age of children with Down syndrome was 8.36 years. More than 31% ($n = 13$) of the children with Down syndrome were under the age of 7, 56.1% ($n = 23$) were between 7 and 14 years of age, and less than 13% ($n = 5$) were more than 14 years of age. Most of

Table 1: Means, Standard Deviations, and Ranges for Demographic Variables

	M	SD	Range
Number of children in the family	3.43	1.53	2 - 10
Maternal age (years)	41.70	5.21	31 - 54
Maternal age when child with Down syndrome was born	33.34	4.78	23 - 44
Maternal education (years)	14.97	2.55	8 - 24
Maternal employment outside the home (hours per week)	21.46	16.34	0 - 45
Age of child with Down syndrome (years)	8.36	4.33	1 - 18
Sibling age (years)	11.46	3.15	7 - 18

the siblings were older than the children with Down syndrome. More than forty percent ($n = 17$) were older sisters, 31.7% ($n = 13$) older brothers, 14.6% ($n = 6$) younger sisters, and 12.2% ($n = 5$) younger brothers.

Procedure

Institutional review board approvals of the study were obtained before its initiation. Families who agreed to participate in the study were mailed a packet that included an introductory letter, a self-report questionnaire for each family member who expressed interest in participating in the study, and stamped, postage-paid envelopes. If a family included more than one nondisabled sibling, data from the sibling closest in age to the child with Down syndrome were used. Family members were asked to return completed questionnaires within 2 weeks. Follow-up postcard reminders were sent to nonrespondents after 3 weeks. Telephone calls were made to those family members who had not responded to the postcard reminders after 1 week.

Measures

Family variables. Four family variables (family demands, family resources, family problem-solving communication, and family coping) were assessed with measures designed and tested by the researchers who developed the framework guiding this research, the

resiliency model. All four measures have been widely used, and they are psychometrically sound with adequate reliability and validity (McCubbin et al., 1996).

The Family Inventory of Life Events (FILE) (McCubbin, Patterson, & Wilson, 1983) was used to assess family demands. This 71-item self-report instrument was designed to assess both the normative and nonnormative family life events, transitions, and strains a family unit may have experienced during the past year. Higher scores indicate greater stress. The alpha coefficient for the total scale was reported as .81, and test-retest reliability was reported as .80. For this sample, the alpha coefficient was .83.

The Family Inventory of Resources for Management (FIRM) (McCubbin, Comeau, & Harkins, 1991) was used to assess family resources. Three subscales were used in this study: Family Strengths I: Esteem and Communication, Family Strengths II: Mastery and Health, and Extended Family Support. A family resource score was computed by summing the three subscales. Alpha coefficients for the subscales were reported to range from .62 for the Extended Family Support subscale to .85 for the remaining subscales. For this sample, the alpha coefficients were .66 for the Extended Family Support subscale, .80 for Family Strengths I, and .82 for Family Strengths II.

The Family Problem-Solving Communication Index (FPSC) (McCubbin, McCubbin, & Thompson, 1988/1996) was used to assess the specific communication style that families use to manage and solve problems and conflicts in various types of stressful situations. The 10-item instrument has two subscales: Affirming Communication (alpha coefficient = .86) and Incendiary Communication (alpha coefficient = .78). The alpha coefficient for the total instrument was reported as .89. For this sample, the alpha coefficient for the total instrument was .87.

The Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin, Olson, & Larson, 1981/1996) was used to assess coping strategies used by the family. F-COPES is a 30-item self-report instrument. Higher scores represent an increase in the number of coping strategies used by the family. The alpha coefficient for the total scale has been reported as .87, and the test-retest reliability for the total scale has been reported as .81. The alpha coefficient for the total scale for the present sample was .97.

Demographic information was obtained using the Family System Information Form. This form was used by the investigator in prior research concerning families that include a child with Down syndrome.

Sibling well-being. The Child Behavior Checklist (CBCL) (Achenbach, 1991) was used to assess maternal perceptions of the sibling's behavior and social competencies. There are 20 social competence items and 118 behavioral problem items on the CBCL. The CBCL yields standardized scores for social competence and behavior. The CBCL has a test-retest reliability of .84 to .97 and is psychometrically sound with adequate reliability and validity (Freeman, 1985).

The Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1986) was used to assess how siblings felt about themselves. It is the most widely used measure of self-concept for children. The Piers-Harris scale consists of 80 first-person statements that require a "yes" or "no" response. A high total score indicates a favorable self-concept. Internal consistency coefficients for the total score have ranged from .88 to .97 across 10 studies in a large standardization sample. Test-retest reliability coefficients were reported to range from .69 to .96 across 12 studies. There is evidence of adequate construct validity based on factor analyses and meaningful correlations with other self-concept measures.

Data Analysis

All data were analyzed using the Statistical Package for the Social Sciences (SPSS 9.0). First, descriptive statistics were computed for the major study variables and the demographic variables. Correlation analysis was then used to explore relationships among the major study variables and the demographic variables.

RESULTS

Means, standard deviations, and ranges for the major study variables are summarized in Table 2. Mothers completed all the measures, except for the Piers Harris, which was completed by siblings.

Table 2: Means, Standard Deviations, and Ranges for the Major Study Variables

Variable		M	SD	Range
Family	Family demands (FILE)	345.87	248.88	25 - 964
	Family resources (FIRM)	83.04	10.40	65 - 108
	Family coping (F-COPES)	107.29	13.87	77 - 136
	Family problem solving (FPSC)	20.95	4.77	8 - 30
Sibling	Total social competence (CBCL)	53.24	8.75	35 - 72
	Total behavior problems (CBCL)	44.88	10.87	29 - 69
	Internalizing (CBCL)	47.70	9.18	31 - 71
	Externalizing (CBCL)	46.08	8.24	33 - 68
Self-concept (Piers Harris)		60.58	8.53	39 - 79

Note: The Piers Harris were completed by siblings. All other measures were completed by mothers. Scores from the CBCL and the Piers Harris are mean *T*-scores computed to the normative mean of 50.00.

Family Variables

The mean FILE score was 345.87, indicating a moderate level of family demands. (McCubbin, Thompson, et al., 1996). The mean scores for two of the subscales of the FIRM were lower than the norm (mean Family Strengths II: Mastery and Health score 37, norm 39, and mean Extended Family Support score 8.7, norm 9). The mean for the third subscale of the FIRM, Family Strengths I: Esteem and Communication subscale was 37.2; the norm was 35. Higher scores on subscales of the FIRM indicate more resources. The mean F-COPES score was 107.29, indicating a higher level of coping than the norm of 95.38 for White nuclear families.

Sibling Well-Being

Social competence and behavioral problems. The mean standardized score for total social competence was 53.24 ($SD = 8.75$). One sibling had a total social competence score in the clinical range (below the second percentile of the normative sample) (Achenbach, 1991). The standardized mean scores for behavior problems (i.e. total behavior problems, internalization, externalization) were 44.88 ($SD = 10.87$), 47.00 ($SD = 9.18$), and 46.08 ($SD = 8.24$), respectively. Four of the siblings had total behavior problem scores in the clinical range (below the second percentile of the normative sample). According to these

findings, only four siblings were considered to be at risk for behavioral maladjustment (one sibling had both a total social competence score and a total behavior problem in the clinical range).

Self-concept. A total self-concept score of 60 is considered to be above average (Piers & Harris, 1986). For this sample, scores on the Piers-Harris ranged from 39 to 72, with the mean score being 60.58 ($SD = 8.53$). This finding indicates that overall, the siblings in this sample had favorable self-concepts.

Correlational Analysis

Results from the descriptive statistics and bivariate scatterplots indicated that the assumptions required for correlational analysis (e.g., evidence of normal distribution, approximately equal variability, linear relationships between variables) were not seriously violated. Therefore, a correlation matrix was generated for the major study variables and select demographic variables (e.g., maternal age, maternal education, family income, number of children, age of child with Down syndrome, sibling age). Examination of the correlation matrix revealed that none of the demographic variables was significantly associated, $p < .05$, with one or more of the sibling well-being variables. Correlations among family variables and sibling well-being variables are summarized in Table 3.

Associations Between Family Variables and Sibling Well-Being Variables

As shown in Table 3, all four family variables (i.e., family demands, family resources, family problem-solving communication, and family coping) were significantly associated with one or more of the sibling well-being variables. There was a significant positive association between family demands and behavior problems ($r = .43, p < .05$). The family demands variable was significantly inversely associated with social competence ($r = -.34, p < .05$) and self-concept ($r = -.35, p < .05$). Mothers who reported lower levels of family demands reported lower levels of sibling behavior problems and higher levels of sibling social competence. Siblings from families reporting lower levels of family demands reported higher self-concepts.

Family resources were significantly associated with social competence ($r = .47, p < .01$) and self-concept ($r = .34, p < .05$). Mothers who

Table 3: Correlations Between Major Study Variables

	1	2	3	4	5	6	7
Family							
1. Demands	1.00						
2. Resources	-.41**	1.00					
3. Coping	-.11	.47**	1.00				
4. Problem solving	-.39*	.50**	.30	1.00			
Sibling							
5. Social competence	-.34*	.47**	.39*	.50**	1.00		
6. Behavior problems	.43*	-.23	-.29	-.33	-.43*	1.00	
7. Self-concept	-.35*	.34*	.11	.22	.18	-.39*	1.00

Note: Self-concept (Piers Harris) measure was completed by siblings. All other measures were completed by mothers.

reported greater family resources reported higher levels of sibling social competence. Siblings from families reporting greater family resources reported high self-concepts.

There was a significant positive association between family coping and social competence ($r = .39, p < .05$). There was also a significant positive association between problem-solving communication and social competence ($r = .50, p < .01$). Mothers who reported higher levels of family coping and higher levels of affirming problem-solving communication in their families reported higher levels of sibling social competence.

DISCUSSION

The results of this study indicate that for many siblings, the experience of living in a family that includes a child with Down syndrome may be a positive, growth producing experience. Family variables, such as those described in the Resiliency Model (McCubbin & McCubbin, 1993), may play a critical role in determining how siblings of children with Down syndrome respond.

As a group, siblings in this study had above average self-concepts. In addition, maternal reports typically indicated that these siblings were socially competent, with a low incidence of behavior problems. Associations among the family variables and the sibling well-being variables were all in the expected directions; however, some were not statistically significant. In general, sibling well-being was higher in

families with lower levels of family demands, greater family resources, higher levels of family coping, and higher levels of affirming problem-solving communication.

The finding that most of the mothers in this sample described the sibling as socially competent with a low incidence of behavior problems provides support for the findings from three of the earlier studies concerning siblings of children with Down syndrome (Carr, 1988; Gath, 1972; Gath & Gumley, 1987). The finding that the mean self-concept score for siblings in this sample was higher than the mean self-concept score for the normative sample is consistent with the findings from the work by Dyson and her associates (Dyson, Edgar, & Crnic, 1989; Dyson & Fewell, 1989).

Findings from this study provide support for the argument by Grossman (1972) that the presence of a child who is developmentally delayed can enhance a family's normal development or at least not hinder it. Grossman reported that whereas 45% of the siblings in her study felt that they had suffered from being the sibling of a person with developmental delays, an equal percentage of siblings felt that they had benefited from the experience, citing increased understanding, tolerance, compassion, and appreciation of their own good health and intelligence. One of the older siblings in the current study was very eloquent when she described how she has benefited from growing up with a brother who has Down syndrome.

He has taught me about patience, love, and happiness. He has shown me the bond between siblings, something which is one of the most important things in life. . . . He has helped me to overcome many of my inner struggles, leaving me more freedom to volunteer in peace, to forgive those who have hurt me, to bring love and trust into the world, and to fulfill my dream—to work with the poor who have AIDS.

One of the younger siblings wrote, "She has taught me patience and acceptance. She helps me to see how much I have, and that I should appreciate every minute of my life." A third sibling wrote, "She has taught me courage—sticking with things."

Several limitations in this research should be noted. First, the sample consisted of volunteers motivated to participate in research. Families in this study were, for the most part, White, two parent, reasonably well educated, and middle to upper class. Sample characteristics such as these warrant caution in any attempt to generalize the find-

ings beyond the study sample. Future studies need to include a more diverse sample of families.

A second limitation is that, despite efforts to obtain data from multiple family members (i.e., mothers, fathers, siblings), only 28 fathers from the 86 families in the larger study returned completed questionnaires. In addition, many of the siblings were either too young (under the age of seven) or too old (more than 18 years of age) to complete the sibling measures. Failure to obtain completed questionnaires from multiple family members for the majority of the families in the larger study resulted in the final sample size for this study being relatively small. In addition, limited participation by fathers resulted in the focus of this report being limited to maternal perceptions of family variables and sibling well-being. Future studies must include creative approaches to recruit and retain fathers. In addition, either the age range for siblings needs to be more narrowly defined, or age-appropriate measures need to be found for siblings more than 18 years of age.

This study was cross-sectional. In the future, longitudinal studies are needed to sort out the direction of the effects. Siblings with higher self-concepts and fewer behavioral problems will most likely decrease family demands and increase family resources. In addition, parents are probably more likely to use affirming communication when siblings are socially competent, with a low incidence of behavior problems. Therefore, the effects are most likely multidirectional and complex.

IMPLICATIONS FOR FAMILY NURSING PRACTICE

Findings from this study provide support for nurses and other health care providers using the Resiliency Model (McCubbin & McCubbin, 1993) to guide their assessment of and their work with families of children with Down syndrome. Three components from the Resiliency Model were significantly associated with sibling well-being (family demands, family resources, and family problem-solving and coping). These variables are modifiable, unlike many of the variables (e.g., age, sex, or birth order) that were examined in earlier studies concerning siblings of children with Down syndrome.

The identification of modifiable family variables is important in the development of family-centered interventions for siblings of chil-

dren with Down syndrome. For example, if the mother of a hospitalized child with Down syndrome asks a nurse for help in dealing with her other child who is "always fighting and getting into trouble," the nurse needs to help the mother realize that the child's behavior may be related to family variables, such as family demands, family resources, family problem-solving communication, or family coping. Maybe an unusual pileup in family demands has taxed family resources, and meeting the needs of the child with Down syndrome has taken precedence over meeting the needs of other family members. In this case, interventions that focus on finding ways to decrease family demands and increase family resources will be the most effective. Perhaps the family has ample resources to manage the unusual pileup of family demands, but their typical style of problem-solving communication is incendiary. If this is the case, interventions targeted at helping the family to develop a more affirming style of problem-solving communication will be more successful.

Ideally, nurses working with families of children with Down syndrome will think about the other children in the family long before they start showing negative consequences. For example, if nurses are interacting with a family on a regular basis because of ongoing health concerns for the child with Down syndrome, they need to ask about the other family members. This may include asking about the type of activities the other children in the family participate in, their performance in school, their peer relationships, and the existence of any behavior problems. When siblings of children with Down syndrome come for their well-child visits, nurses have the opportunity to directly assess how these children are doing. Nurses can ask siblings about their activities, peer relationships, relationships with the child who has Down syndrome, and thoughts about how things are going in their family. In addition, nurses can make siblings of children with Down syndrome and their parents aware of resources specifically developed for siblings of children with chronic conditions. One excellent resource is the Sibling Support Project, a project directed by Donald Meyer that is located at Children's Hospital and Medical Center in Seattle. It is easily accessible on the Web at <http://www.chmc.org/departmt/sibsupp>.

SUMMARY

In summary, this research adds a critical piece, the sibling piece, to a fascinating puzzle concerning how families respond to the multiple challenges associated with raising a child with Down syndrome. The findings add to the minimal knowledge that exists concerning sibling well-being in families of children with Down syndrome. The findings contribute to our understanding of the underlying processes associated with differing outcomes for siblings of children with Down syndrome. Efforts to intervene with families that include a child with Down syndrome will be more effective if health care providers recognize the individual, family, and community properties and processes that interact and shape how individuals and families respond to the challenges associated with raising a child with Down syndrome.

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