

# Families of Children with Down Syndrome: Responding to “A Change in Plans” with Resilience

Marcia Van Riper, RN, PhD

The purpose of the present investigation, which was guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation, was twofold: (a) to describe maternal perceptions of parental and family adaptation in families raising a child with Down syndrome, and (b) to examine linkages between family demands, family resources, family problem solving and coping, and family adaptation in families of children with Down syndrome. Seventy-six mothers completed mailed questionnaires. Seventy percent of the mothers rated their family's overall functioning as either a 4 or a 5 on a 5-point scale (1 = *poor*; 5 = *excellent*). In their written comments, most mothers reported that their family was doing well or very well. Three family variables (i.e., family demands, family resources, and family problem-solving communication) were significantly associated with family adaptation. These results provide support for the belief that many families of children with Down syndrome respond to “a change of plans” with resilience. That is, they are able to endure, survive, and even thrive in the face of ongoing challenges associated with raising a child with Down syndrome.

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**D**OWN SYNDROME IS the most common chromosomal cause of intellectual disabilities (Cohen, 2005; Patterson & Costa, 2005). Despite the widespread use of prenatal screening for Down syndrome, the incidence of Down syndrome remains steady, occurring once in every 800–1,000 live births (Cohen, 2005; Patterson, 1999). According to the website for the National Down Syndrome Society (2003), there are more than 350,000 individuals in the United States who have Down syndrome. Individuals with Down syndrome come from all races, religions, ethnic backgrounds, and socioeconomic status.

Because of the unique health, developmental, and educational concerns commonly associated with Down syndrome, families of children with Down syndrome generally experience higher levels of stress than families with typically developing children (Baker et al., 2003; Cheng & Tang,

1995; Hedov, Anneren, & Wikblad, 2002; Lam & Mackenzie, 2002; Olsson & Hwang, 2003; Padeliadu, 1998; Pelchat et al., 1999; Roach, Orsmond, & Barratt, 1999; Sanders & Morgan, 1997). In prior decades, it was often assumed that the increased stress associated with raising a child with Down syndrome would result in negative consequences for both individual family members and the family as a whole (Ferguson, 2002). Currently, there is growing consensus that this is not always the case. Although some families of children with Down syndrome have difficulty adapting to the increased stress, other families adapt successfully and even thrive (Cahill & Glidden, 1996; Cunningham, 1996; Flaherty & Glidden, 2000; Gath, 1990; King, Scollon, Ramsey, & Williams, 2000; Scott, Atkinson, Minton, & Bowman, 1997; Van Riper, 1999a, 1999b; Van Riper, Pridham, & Ryff, 1992; Van Riper, Ryff, & Pridham, 1992).

Unfortunately, current understanding of why some families adapt successfully to the increased stress associated with raising a child with Down syndrome whereas others do not is rather limited. This is due, in part, to the long-standing practice of looking for stress, burden, and dysfunction in families of children with disabilities (Ferguson, 2002; Glidden, 1993; Helff & Glidden, 1998). Fortunately, research concerning families of chil-

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*From the Carolina Center for Genome Sciences, School of Nursing, University of North Carolina at Chapel Hill, Chapel Hill, NC.*

*Address correspondence and reprint request to Marcia Van Riper, RN, PhD, School of Nursing, University of North Carolina at Chapel Hill, Chapel Hill, NC.*

*E-mail: vanriper@email.unc.edu*

*0882-5963/\$ - see front matter*

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dren with disabilities is gradually shifting from a focus on dysfunction to a focus on family strengths and resilience (Abbott & Meredith, 1986; Flaherty & Glidden, 2000; Helff & Glidden, 1998; Kearney & Griffen, 2001; King et al., 2000; Nachshen, Woodford, & Minnes, 2003; Saloviita, Italinna, & Leinonen, 2003; Scorgie & Sobsey, 2000; Sloper, Knussen, Turner, & Cunningham, 1991; Stainton & Besser, 1998; Van Riper, 1999b).

McCubbin (1999), a family researcher interested in resilient families, contends that well-being in families can be best understood by studying the natural capabilities of families to endure, survive, and even thrive in the face of crises. McCubbin, Thompson, and McCubbin (1996, p. 6) have defined "resilience" as:

the positive behavioral patterns and functional competence individuals and families demonstrate under stressful or adverse circumstances, which determines the family's ability to recover by maintaining integrity as a unit while ensuring and, where necessary, restoring the well-being of family members and the family unit as a whole.

As part of their ongoing efforts to understand resilience in families, McCubbin and McCubbin (1993) developed the Resiliency Model of Family Stress, Adjustment, and Adaptation. The resiliency model, which builds on the ABCX stress model of Hill (1949) and on later family stress models (McCubbin & Patterson, 1983; McCubbin, Thompson et al., 1996), is organized into two phases: the adjustment phase and the adaptation phase. The adjustment phase depicts how families respond to events that do not present major hardships and only require minor changes in how the family is currently functioning, or the initial response of the family to a more major event. The adaptation phase focuses on how families respond to major transitions or hardships that require fundamental structural or systematic changes in family functioning.

Because of the many ongoing challenges associated with raising a child with Down syndrome, the adaptation phase is probably most applicable to these families. Successful family adaptation (bonadaptation) occurs when the family is able to achieve a balance between the needs of the child with Down syndrome, the needs of the family as a whole, and the needs of other family members. Unsuccessful family adaptation (maladaptation) occurs when the family is unable to achieve this balance. High levels of parental well-being and overall family functioning suggest successful adaptation, whereas low

levels of parental well-being and overall family functioning suggest unsuccessful adaptation (McCubbin & McCubbin, 1993).

## PURPOSE

The purpose of the present investigation, which was guided by the Resiliency Model of Family Stress, Adjustment, and Adaptation (McCubbin & McCubbin, 1993), was twofold: (a) to describe maternal perceptions of parental and family adaptation in families raising a child with Down syndrome, and (b) to examine linkages between family demands, family resources, family problem solving and coping, and adaptation in families of children with Down syndrome. Parental adaptation includes both the physical and psychological well-being of the parents. Family adaptation is defined as the outcome of family efforts to bring a new level of balance and functioning to a stressful or crisis situation (McCubbin, Thompson et al., 1996). Family demands include the demands on or in the family system created by (a) a family member who has a chronic condition, (b) family life cycle changes, (c) prior unresolved family strains, (d) consequences of family efforts to cope, and (e) ambiguity at both the intrafamilial and the societal level (McCubbin, Patterson, & Wilson, 1996). Family resources are the strengths and capabilities of individual family members, the family working as a unit, and the community (McCubbin, Comeau, & Harkins, 1996). Family problem solving and coping are actions taken by individual family members or the family functioning as a unit to manage stresses and hardships, acquire resources, reduce family system tension, and shape or reshape family appraisal (McCubbin, Larson, & Olson, 1996).

## LITERATURE REVIEW

### Parental Adaptation

Historically, researchers investigating the experience of raising a child with a disability have focused on a wide range of negative outcomes that parents, especially mothers, might experience. Some of the negative outcomes that have been reported for parents of children with Down syndrome and other disabilities include: prolonged crisis or chronic sorrow (Damrosch & Perry, 1989; Olshansky, 1962; Wikler, Wasow, & Hatfield,

1981), altered self-concept (Childs, 1985), decreased self-esteem (Cummings, 1976), depression (Bristol, Gallagher, & Schopler, 1988; Cummings, 1976; Cummings, Bayley, & Rie, 1966; Friedrich, Wiltner, & Cohen, 1985; Olsson & Hwang, 2001; Spangenberg & Theron, 2000), social isolation (Birnbaum, 1970; Featherstone 1980; Seltzer, Greenberg, Floyd, Pettee, & Hong, 2001), severe emotional distress (Drillien, 1966), increased marital problems (Bristol et al., 1988; Friedrich & Friedrich, 1981; Friedrich et al., 1985; Gath & Gumley, 1984), and low rates of employment or delayed entry into the workforce (Shearn & Todd, 2000; Seltzer et al., 2001).

The current shift toward a focus on resilience and adaptation started gaining momentum in the late 1980s. Abbott and Meredith (1986) identified strengths in parents of children with mental retardation, such as increased patience, greater appreciation for simple aspects of life, and increased compassion. Trute (1988) identified factors (i.e., functioning of the parental subsystem and skillful utilization of family and friendship network) associated with positive adjustment in families of children with disabilities. Other investigators reported no significant difference between parents of children with disabilities and parents of nondisabled children on measures of self-esteem (Harris & McHale, 1989), parental competence (Gowen, Johnson-Martin, Goldman, & Applebaum, 1989), psychological well-being (Van Riper, Ryff et al., 1992), dyadic functioning (Van Riper, Ryff et al., 1992), and marital satisfaction (Kazak & Marvin, 1984; Waisbren, 1980).

Investigators interested in long-term parental adjustment to a child's disability have noted that parents may initially experience negative outcomes, such as depression and emotional distress, but these adjustment problems usually decrease in time, and that positive outcomes, such as psychological well-being, personal growth, improved relations with others, changes in philosophical or spiritual values, and satisfaction with parenting, are likely outcomes (Blacher, 2001; Flaherty & Glidden, 2000; Glidden & Schoolcraft, 2003; King et al., 2000; Landsman, 1999; Seltzer et al., 2001; Seltzer & Krauss, 1989; Scorgie & Sobsey, 2000; Van Riper & Selder, 1989). In a content analysis of 60 books written by parents of children with disabilities (Mullins, 1987), the majority of parents indicated that their lives had increased meaning and enrichment because of their experiences with their children with disabilities.

Recently, there has been growing recognition that the experience of parenting a child with a disability is a paradox filled with conflicting emotions. Parents of children with disabilities not only experience pain, despair, suffering, and sorrow, but also experience joy, hope, happiness, and optimism (Hornby, 1992; Kearney & Griffen, 2001; Lam & Mackenzie, 2002; Larson, 1998; Seideman & Kleine, 1995). For example, a mother of a 3-year-old boy with Down syndrome who is not walking yet and only speaks a few words may wish that he would walk and talk like typically developing children, yet she may also express a deep love and affection for her child just the way he is. The ability of a parent to embrace the paradox of disability may ultimately enhance parental and family adaptation. According to Larson, embracing the paradox of their child's disability helps mothers to overcome obstacles and regain their sense of control by fueling their optimism in maternal work. Embracing the paradox can also generate profound internal spiritual and emotional changes.

### Family Adaptation

There have been at least three programs of research concerning family adaptation following the birth of a child with Down syndrome. Two of these were started in the early 1970s and they were conducted in the United Kingdom (Cunningham, 1996; Gath, 1990). The third was started in the late 1980s and is being conducted in the United States (Van Riper, 1999b). Findings from all three research programs suggest that negative consequences are not inevitable outcomes of the increased stress associated with raising a child with Down syndrome.

Gath (1985) noted that, when things go wrong for a family, the very existence of a child with Down syndrome brings vulnerable areas within the family, such as personality problems, immaturity, and precarious relationships into sharp focus. She also noted that it is unjust to the child with Down syndrome to regard these problems as inevitable outcomes of the increased stress associated with raising a child with Down syndrome. She concluded that many families of children with Down syndrome are able to function in a healthy way, and a significant number have found their lives enriched by what was originally considered to be an intolerable burden.

In a report of key findings from his ongoing program of research, which is one of the largest

and most detailed multifactorial programs of research concerning families of children with Down syndrome, Cunningham (1996, p. 87) wrote:

The overriding impression of the families and their child with Down syndrome is one of normality. The factors that influence the well being of all members are largely the same as those influencing any child or family. The majority of families do not exhibit pathology as a consequence of having a child with Down syndrome. Indeed, the evidence points to positive effects for many families when one member has Down syndrome.

Van Riper (1999b) has reported findings similar to those reported by Gath and Cunningham. According to Van Riper, findings to date “indicate that while the birth of a child with Down syndrome involves a “change of plans” for families, it does not have to be a negative experience. In fact, for many families, it is a positive, growth-producing experience” (p. 3). One parent of a child with Down syndrome wrote (pp. 3–4):

“Our entire family and marriage are stronger. It has changed our view of the world, our view of ourselves, and others. It has made us more giving and less selfish. It has drawn us closer to God. It has caused us to be more concerned about others who are different. It has shown us what we value in life—relationships, not power and wealth. It has made us more content to just be!”

Findings from these three programs of research concerning family adaptation following the birth of a child with Down syndrome are supported by findings from the larger body of research concerning family adaptation in families that include a child with a chronic illness or disability (see reviews by Faux, 1998; Hastings & Taunt, 2002; Helff & Glidden, 1998; Knafl, 1998; Miles, 2003). In addition, most of the book chapters (Beck, 2002; Meyers, 1995; O’Neil, 2002; Pueschel, 2002) and books (Beck, 1999; Berube, 1998; Stallings, & Cook, 1997) that have been written by parents of children with Down syndrome support these findings.

## Family Variables That May Influence Family Adaptation

### *Family Demands*

In addition to the pile-up of demands (e.g., stresses, strains, and transitions) faced by families with typically developing children, families of children with Down syndrome are subject to additional demands, such as increased caregiving difficulties, changes in roles, and increased time

demands (Seideman & Kleine, 1995; Shearn & Todd, 2000; Van Riper, 1999b; Van Riper & Selder, 1989). Roach et al. (1999) found that parents of children with Down syndrome reported more caregiving difficulties, child-related stress, and parent-related stress than did parents of typically developing children. In a study by Scorgie and Sobsey (2000), many parents of children with disabilities indicated that they had acquired new roles, such as advocate, teacher, writer, parent-group leader, conference speaker, and member of advisory councils for schools, hospitals, and agencies representing individuals with disabilities.

Increased caregiving difficulties and changes in roles often result in increased time demands for parents of children with disabilities (Barnett & Boyce, 1995; Lam & Mackenzie, 2002; Padelidu, 1998). Mothers of children with Down syndrome have reported that, due to increased time demands, they needed to reduce their time in paid work by about 7 hours/week and to increase their childcare time by about 9 hours/week (Barnett & Boyce, 1995). For some mothers of children with disabilities, lack of opportunities to engage in employment resulted in feelings of isolation, lack of fulfillment, and low self-esteem (Shearn & Todd, 2000). There is also evidence that increased time demands can result in some parents of children with disabilities having less time to participate in valued social and recreational activities than do parents of nondisabled children (Barnett & Boyce, 1995; Scorgie & Sobsey, 2000). According to Olsson and Hwang (2003), restricted social life and time restrictions were the most evident and bothersome stressors for Swedish parents of children with disabilities. When the pile-up of demands on or within the family unit is high, meeting the needs of the child with Down syndrome may take precedence in meeting the needs of other family members. Thus, it was predicted that there would be a negative association between family demands and family adaptation.

### *Family Resources*

Family resources play an important role in how families adapt to ongoing challenges associated with raising a child with a chronic condition (Blacher & Hatton, 2001; Chen & Tang, 1997; Patterson, 1995). According to McCubbin and McCubbin (1993), families with adequate resources have a better chance of managing stress and restoring balance in their lives than families with limited resources. In a longitudinal study by Cunningham (1996), there was a significant positive

association between utilitarian family resources (e.g., housing, finances, and employment) and well-being in families of children with Down syndrome. Dyson (1997) reported a significant negative association between family psychological resources (e.g., family emphasis on personal growth, family cohesion, and family support) and parental stress in families that included a child with a disability. In a review of existing literature on family stress and burden in families of children with intellectual disabilities, Blacher and Hatton (2001) concluded that “the impact of disability on the family is clearly reflective of the political and economic climate, and, as these change, so too will the level of burden” (p. 280). For this study, a positive association between family resources and family adaptation in families of children with Down syndrome was predicted.

### *Family Problem Solving and Coping*

Family adaptation in families dealing with stressful situations depends, in part, on the range and depth of the family’s repertoire of problem solving and coping strategies (McCubbin & McCubbin, 1993). Grant and Whittell (2000) found that families of children with disabilities demonstrated considerable resilience in their everyday coping, as illustrated by the number and range of coping strategies that they displayed. Families found behavioral/problem solving and cognitive coping strategies to be more useful than stress reduction techniques. Hastings, Allen, McDermott, and Still (2002) noted that reframing coping strategies were positively associated with maternal perceptions of the child as a source of happiness and fulfillment and as a source of strength and family closeness.

Although many families of children with Down syndrome have reported using passive and avoidant coping strategies (Cheng & Tang, 1995; Cunningham, 1996), these strategies have not been found to be as effective in helping families deal with the challenges associated with raising a child with Down syndrome. In the longitudinal study by Cunningham, the use of wishful thinking, a passive coping strategy, was negatively associated with measures of individual and family well-being. Avoidance coping strategies have been significantly correlated with both depression and anxiety in parents of children with Down syndrome (Spangenberg & Theron, 2000).

Another factor that may influence family adaptation to stressful situations is the type of communication family members use to problem-solve.

Families with an affirming style of problem-solving communication (conveys support and caring and exerts a calming influence) have been found to adapt more successfully to stressful situations than families with an incendiary style of problem-solving communication (inflames and exacerbates a stressful situation) (Leske & Jiricka, 1998; McCubbin et al., 1996). In this study, it was predicted that families who reported using a variety of strategies to problem-solve and cope would report better parental and family adaptation than would families who reported using a limited number of strategies, especially if the strategies used were passive or avoidant strategies. In addition, a positive association between problem-solving communication and family adaptation was predicted.

### Summary

According to existing research on families of children with Down syndrome and other disabilities, families of children with disabilities generally experienced higher levels of stress than did families of typically developing children. Although some families of children with disabilities found it difficult to adapt to the increased stress associated with parenting a child with a disability, other families were resilient and thrived. Currently, questions concerning why this occurs remain. That is, it remains unclear which factors play a critical role in determining how a family will respond to the challenges associated with raising a child with a disability. Therefore, this investigation was conducted to (a) describe maternal perceptions of parental and family adaptation in families raising a child with Down syndrome, and (b) examine linkages between family demands, family resources, family problem solving and coping, and family adaptation in families of children with Down syndrome. The guiding framework was the Resiliency Model of Family Stress, Adjustment, and Adaptation. A negative association was predicted between family demands and family adaptation. Positive associations were predicted between the other family variables (i.e., family resources, family problem solving and coping) and family adaptation.

## METHODS

### Design

A descriptive correlational design was used. This study was part of a larger study performed to explore

sibling well-being in families of children with Down syndrome (Van Riper, 1999b). Findings concerning associations between family variables and sibling well-being in 41 families from the larger study have been published (Van Riper, 2000).

## Sample

The sample for this study was a volunteer sample of 76 families who had a child with Down syndrome. 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 mail sent to families who had participated in previous research of this investigator. Of the 98 families that expressed interest in participating in the larger study, 86 families (87.8% response rate) returned at least one questionnaire (81 mothers, 28 fathers, and 69 siblings returned completed questionnaires). Data from 76 mothers who returned completed questionnaires are the focus of this report (questionnaires from five of the mothers missed too much data to be included in the final analysis).

The majority of families were White (95%), two-parent (95%), and middle-class to upper-class (38% had family incomes between US\$25,000 and US\$55,000; 50% had family incomes greater than US\$55,000). Mothers ranged in age from 30 to 61 years. The mean age of mothers upon the birth of their child with Down syndrome was 33.4 years ( $SD = 4.83$ ). The mean number of years of education for mothers was 14.5 years ( $SD = 3.73$ ). Thirty-eight percent ( $n = 29$ ) of the mothers were employed outside the home full time (30 hours or more per week), 28% ( $n = 21$ ) were employed part time (less than 30 hours/week), and 34% ( $n = 26$ ) were not employed.

The average age of children with Down syndrome was 7.5 years. More than 44% ( $n = 34$ ) of the children with Down syndrome were under the age of 7 years; 40.8% ( $n = 31$ ) were between 7 and 14 years; and less than 15% ( $n = 11$ ) were more than 14 years. Family size ranged from 2 children ( $n = 23$ ) to 12 children ( $n = 1$ ); the average number of children was 3. The majority of families (> 90%) belonged to some type of organization for children with chronic conditions. More than 52% ( $n = 40$ ) belonged to a local support group.

## Procedure

Institutional review board approval of the study was obtained before its initiation. Families that

agreed to participate in the larger 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. 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

### *Demographic Information*

The Family System Information Form was used to obtain demographic information, such as age, income, and education. This form was used by the investigator in prior research concerning families of children with Down syndrome (Van Riper, 1999a).

### *Individual Adaptation*

To assess individual adaptation, parents were asked to rate the overall physical well-being of each family member on a 5-point scale (1 = *poor*; 5 = *excellent*). Then they were asked to rate the overall psychological well-being of each family member on the same 5-point scale.

### *Family Adaptation*

To assess family adaptation, parents were asked to rate how their family functioned overall on a 5-point scale (1 = *poor*; 5 = *excellent*). In addition, parents were asked, "Please describe how your family is doing now."

### *Family Demands*

The Family Inventory of Life Events (FILE) (McCubbin, Patterson et al., 1996) was used to assess family demands. This 71-item self-administered instrument was designed to assess both normative and nonnormative family life events, transitions, and strains. Each of the 71 life events is weighted as to how stressful it is. For example, the most stressful life event listed on the FILE is *A child member died*. The weighted score for this item is 99. The least stressful life event listed on the FILE is *A member purchased a car or other major items*. The weighted score for this item is 19. Respondents are asked to check yes or no as to whether each life event happened in their family during the past year. The weighted scores for each

of the yes responses are summed to yield a total family demands score. Higher scores indicate higher family demands. This instrument has been used with a variety of samples, and it has well-established validity and reliability. The  $\alpha$  coefficient for the total scale was reported as .81, and the test-retest reliability was .80. For this sample, the  $\alpha$  coefficient was .82.

### **Family Resources**

Three subscales (i.e., Family Strengths I: Esteem and Communication; Family Strengths II: Mastery and Health; and Extended Family Support) of the Family Inventory of Resources for Management (FIRM) (McCubbin, Comeau et al., 1996) were used to assess family resources. Respondents indicate on a 4-point Likert-type scale (0 = *not at all*, 1 = *minimally*, 2 = *moderately*, 3 = *very well*) the degree to which each of the 39 items applies to their family. Items include statements such as *We discuss our decisions with other family members before carrying them out* and *We have to nag each other to get things done*. The items for each subscale are summed to get subscale scores after 20 of 39 items are reverse-scored, as indicated by the authors' instructions. For this study, 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 .65 for the Extended Family Support subscale, .82 for Family Strengths I, and .83 for Family Strengths II. The  $\alpha$  coefficient for the family resource score was .85.

### **Family Problem-Solving Communication**

The family problem-solving communication index (FPSC) (McCubbin, McCubbin et al., 1996) was used to assess family problem-solving communication. The FPSC is a self-administered 10-item instrument designed to measure positive and negative patterns in family communication related to family coping. Items include statements such as: "We work to be calm and talk things through" and "We yell and scream at each other." Using a 4-point Likert-type scale (0 = *false*, 1 = *mostly false*, 2 = *mostly true*, 3 = *true*), respondents circle a number corresponding to the degree to which the description is characteristic of behavior in their family. A total score is obtained by summing the responses for all of the items, once three of the items have been reverse-scored to

make all the items positive. The potential range of scores for the total score is 0–30, with higher scores indicating that the family typically uses affirming, rather than incendiary, communication to manage and solve problems and conflicts in various stressful situations. The  $\alpha$  coefficient for the FPSC was reported as .89. For this sample, the  $\alpha$  coefficient for the FPSC was .82.

### **Family Coping**

The Family-Crisis-Oriented Personal Evaluation Scales (F-COPES) (McCubbin, Larson et al., 1996) was used to assess family coping. F-COPES is a self-administered instrument that contains 30 items and utilizes a 5-point Likert-type scale (1 = *strongly disagree*, 2 = *moderately disagree*, 3 = *neither agree nor disagree*, 4 = *moderately agree*, 5 = *strongly agree*). F-COPES scores are obtained by summing the scores for each item once three items had been reverse-scored as specified by the authors' instructions. The potential range of scores for the F-COPES is 30–150. Higher F-COPES scores represent an increase in the number of coping strategies used by the family. The  $\alpha$  coefficient for the F-COPES has been reported as .87. The  $\alpha$  coefficient for the F-COPES for the present sample was .91. Test-retest reliability ( $r = .81$ ) and construct validity have been established for the F-COPES.

### **Data Analysis**

All data were analyzed using the Statistical Package for the Social Sciences (SPSS 11.0, Chicago, IL). First, descriptive statistics were computed for major study variables and demographic variables. Correlation analyses were conducted to explore relationships among major study variables and demographic variables.

## **RESULTS**

Means, standard deviations, and ranges for major study variables are summarized in Table 1. The mean FILE score was 351.4, indicating a moderate level of family demands (McCubbin et al., 1996). The five items reported with the highest percentage by the mothers were: (a) increase in the amount of "outside activities" in which the children are involved (52.6%); (b) increase in the number of tasks or chores that do not get done (38.2%); (c) increased strain on family "money" for food, clothing, energy, and homecare (38.2%); (d) a family member purchased a car or

**Table 1. Means, Standard Deviations, and Ranges for Major Study Variables**

Variables	M	SD	Range
Family demands (FILE)	351.35	251.29	25–1,355
Family resources (FIRM)	83.07	11.85	49–108
Family coping (F-COPES)	107.82	13.16	77–136
Problem solving (FPSC)	21.13	4.98	8–30
Family adaptation	4.12	0.72	2–5
Maternal physical well-being	3.97	0.84	1–5
Maternal psychological well-being	4.14	0.76	3–5
Paternal physical well-being	4.00	0.97	1–5
Paternal psychological well-being	3.99	0.84	2–5

other major items (38.2%); and (e) increase in arguments between parent(s) and children (28.9%). The weighted scores for these five items (indicating how stressful the item is) ranged from 19 to 45, with increase in arguments between parent(s) and children having a score of 45.

The mean scores for the three FIRM subscales were similar to the reported norms: Family Strengths I: Esteem and Communication ( $M = 37.1$ , norm = 35), Family Strengths II: Mastery and Health ( $M = 37.3$ , norm = 39), and Extended Family Support ( $M = 8.9$ , norm = 9). Higher scores on the FIRM subscales indicate more family resources. The mean FPSC score was 21.1, indicating that families in this study tended to use an affirming style of problem-solving communication. That is, they tended to communicate in a calming manner that conveys support and caring. The mean F-COPES score was 107.82, indicating a higher level of coping than the norm of 95.38 for White nuclear families. The five items from the F-COPES with the highest mean scores were: (a) having faith in God ( $M = 4.3$ ); (b) knowing that we have the power to solve major problems ( $M = 4.3$ ); (c) facing problems “head on” and trying to get solutions right away ( $M = 4.2$ ); (d) sharing concerns with close friends ( $M = 4.2$ ); and (e) knowing that we have the strength within our family to solve our problems ( $M = 4.1$ ). Three of these items were from the reframing subscale—a subscale that assesses the family’s capability to redefine stressful events to make them more manageable (McCubbin et al., 1996).

The mean score for physical well-being was 4.0 for both mothers and fathers. For mothers,  $SD = 0.97$ ; for fathers,  $SD = 0.84$ . The range was 1–5 for both mothers and fathers. The mean score for psychological well-being was slightly higher for mothers ( $M = 4.1$ ,  $SD = 0.76$ , range = 3–5) than

for fathers ( $M = 4.0$ ,  $SD = 0.84$ , range = 2–5). The mean score for family adaptation was 4.2 ( $SD = 0.72$ , range = 2–5). Fifty-three mothers (76%) rated their family as either a 4 or a 5 on a 5-point scale (1 = *poor*; 5 = *excellent*). In response to the request for comments regarding how their family was doing, most mothers reported that their family was doing well or very well. Many mothers noted that they were doing much better than they had originally anticipated. One mother wrote:

“Our family is doing exceeding well. There is much love and pride within our family daily. All family members seem to be pursuing individual and family goals/needs satisfactorily. Although we would have preferred a non-Down syndrome child, our child with Down syndrome provides as much love, laughter, and joy, if not more, than we could have ever anticipated.”

The need to constantly juggle multiple demands was a recurrent theme in the mother’s comments. According to one mother:

“We are doing very well. We all try to be individuals and yet keep a close family relationship. We are all interested in each others’ goals, talents, and challenges and try to take an active part in these interests when we can. This means lots of juggling, but we make it work. The key is connecting as a family and communicating. Healthwise, we are all very healthy and grateful.”

Although most mothers reported that their family was doing well or very well, five mothers indicated that their family was having a difficult time or not doing well. One mother wrote:

“Our family has been hanging from a string since N’s birth. We have financially struggled—mentally struggled. Trying to keep in mind the fact that we could lose our boy. We (my husband and I) don’t talk much. Our daughter has grown up a little faster than others. She doesn’t see me much lately. Trying to get enough money to pay a couple months worth of bills... We’ve stayed married so far and kept our house—this is a major accomplishment.”

### Associations Between Major Study Variables

A correlation matrix was generated for major study variables and selected demographic variables (e.g., maternal age, maternal education, family income, number of children, and age of child with Down syndrome). Examination of the correlation matrix revealed that none of the demographic variables was significantly associated ( $p < .05$ ) with family adaptation. Correlations among major study variables are summarized in Table 2.

**Table 2. Correlations Between Major Study Variables**

	1	2	3	4	5
1. Family demands	1.00				
2. Family resources	-.45**	1.00			
3. Family coping	-.06	.43**	1.00		
4. Family problem solving	-.29*	.58**	.30*	1.00	
5. Family adaptation	-.35**	.70**	.17	.53**	1.00

\* $P = .05$ .\*\* $P = .01$ .

Three family variables (i.e., family demands, family resources, and family problem-solving communication) were significantly associated with family adaptation. There was a significant negative association between family demands and family adaptation ( $r = -.35, p < .01$ ). Mothers who reported higher levels of family demands, lifestyle changes, and unresolved strains rated their family adaptation lower. Family resources were significantly associated with family adaptation ( $r = .70, p < .01$ ). Mothers who reported greater family resources rated their family adaptation higher. There was a significant positive relationship between problem-solving communication and family adaptation ( $r = .53, p < .01$ ). Mothers who reported higher level of problem-solving communication in their families rated their family adaptation higher.

## DISCUSSION

Findings from this study provide support for the growing argument that many families are able to respond to the experience of raising a child with a disability, such as Down syndrome, with resilience and adaptive functioning (Cahill & Glidden, 1996; Cunningham, 1996; Flaherty & Glidden, 2000; Gath, 1990; King et al., 2000; Scott et al., 1997; Van Riper, 1999b). Seventy percent of the mothers in this study rated their family's overall functioning as either a 4 or a 5 on a 5-point scale (1 = *poor*; 5 = *excellent*). When mothers were asked to describe how their family was doing at present, most of the responses were very positive. Many included descriptions of individual and family accomplishments. Many also included descriptions of how the experience of raising a child with Down syndrome had resulted in positive consequences for individual family members and the family as a whole. Given the extensive prior literature concerning possible negative consequences associated with raising a child with Down syndrome, such findings are significant and should have an impact on how nurses and other health

care providers care for children with Down syndrome and their families.

A number of comments by mothers in this study reflected the paradox of disability described by Larson (1998). That is, their responses included conflicting emotions, such as joy and sadness. It is essential that nurses and other health care professionals understand what it means for families to embrace the paradox of their child's disability. According to Larson, embracing the paradox is a compromise between acceptance and denial. It is essential for the psychological well-being of parents of children with disabilities because embracing the paradox energizes them and allows for hope, optimism, a positive vision of the future, and personal growth. Nurses can play a key role in helping parents embrace the paradox of their child's disability by providing parents with a safe supportive environment to verbalize their conflicting emotions.

Findings from this study also provide support for the argument that families of children with Down syndrome experience higher levels of stress than families with typically developing children (Cheng & Tang, 1995; Hedov et al., 2002; Lam & Mackenzie, 2002; Olsson & Hwang, 2003; Padelidu, 1998; Pelchat et al., 1999; Roach et al., 1999; Sanders & Morgan, 1997). As a group, families in this study had moderate levels of family demands. However, a number of families had high levels of demands. Fifteen families had demand scores above 500. Written responses by mothers were filled with comments concerning the need for family members to constantly juggle multiple demands. Mothers also frequently commented about time demands and the lack of time for social and recreational activities.

These findings provide support for the belief that many families of children with Down syndrome are resilient. That is, they are able to endure, survive, and even thrive in the face of ongoing challenges associated with raising a child with Down syndrome. Failure of health care providers to acknowledge resilience in families of children with Down syndrome may undermine the inherent capability of these families to "bounce back" from the ongoing challenges they face. It may also lead to strained family-provider relationships. Ultimately, it may result in decreased well-being in families of children with Down syndrome.

The findings from this study provide support for nurses and other health care providers using a theoretical framework, such as the resiliency model, in their work with families of children with Down

syndrome. McDonald, Kysella, Drummond, Martin, and Wiles (n.d.) describe intervening with families using this model. Three variables from the resiliency model (i.e., family demands, family resources, and family problem-solving communication) were significantly associated with family adaptation. Unlike many of the variables examined in prior research concerning families of children with Down syndrome, these variables are modifiable. The identification of modifiable family variables is critical in the development of family-centered interventions for families of children with Down syndrome.

Nurses can promote resilience and adaptation in families of children with Down syndrome by helping families to: (a) recognize multiple stressors, strains, and transitions in their lives (i.e., pile-up of family demands); (b) discuss and implement strategies for reducing family demands (e.g., setting priorities and reducing the number of outside activities family members are involved in); (c) identify and use individual, family, and community resources (e.g., humor, family flexibility, supportive extended family, respite care, local support groups, and Internet resources); (d) expand the range and efficacy of their coping strategies (e.g., increase the use of active strategies such as reframing, mobilize their ability to acquire and accept help, and decrease the use of passive appraisal); and (e) encourage the use of an affirming style of family problem-solving communication (e.g., one that conveys support and caring and exerts a calming influence).

Findings from this study underscore the importance of nurses finding out how individuals and families define the experience of raising a child with Down syndrome. No two individuals or families define the situation in the same way. In addition, individual and family definitions may change in time (Van Riper, Pridham et al., 1992).

Understanding how individuals and families define their situation may help nurses to target their interventions more effectively.

A number of limitations in this research should be noted. First, families who participated in this study were, for the most part, White, two-parent, reasonably well-educated, and middle-class to upper-class. Sample characteristics such as these warrant caution in any attempt to generalize the findings beyond the study sample. Future studies need to include a more diverse group of families. Another limitation is that, despite efforts to obtain data from both mothers and fathers, only 28 fathers from the 86 families in the larger study returned completed questionnaires. As a result, the focus of this report was limited to maternal perceptions. In the future, creative approaches need to be implemented to recruit and retain fathers (Ricci & Hodapp, 2003).

In summary, findings from this research add to the knowledge base concerning resilience in families of children with Down syndrome that currently exists. Nurses can play an important role in promoting resilience and adaptation in families of children with Down syndrome if they recognize and value the natural capabilities of these families to endure, survive, and even thrive in the face of ongoing challenges associated with raising a child with Down syndrome. There has probably always been resilience in families of children with Down syndrome; some have just been too busy searching for dysfunction to notice.

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