

Maternal Perceptions of Family–Provider Relationships and Well-Being in Families of Children with Down Syndrome

Marcia Van Riper^{*}

College of Nursing, The Ohio State University, 1585 Neil Avenue, Columbus, OH 43210
Received 11 February 1998; accepted 20 March 1999

Abstract: The purpose of this study was twofold: (a) to describe parental perceptions of family–provider relationships, and (b) to explore links between parental perceptions of family–provider relationships and well-being in families with children who have Down syndrome. Mailed questionnaires were used to collect data from 94 families that include a child with Down syndrome. Data from 89 mothers are the focus of this report. The results indicate that when mothers of children with Down syndrome believe that their family’s relationship with health care providers is positive and family-centered, they feel more satisfied with the care that their child is receiving and they are more likely to seek help from health care providers. In addition, when a discrepancy exists between what mothers want the family–provider relationship to be and what they believe the relationship is, mothers feel less satisfied with the care that their child is receiving. Finally, higher levels of individual and family well-being are reported by mothers who (a) want, and believe they have, positive family-centered relationships with providers, and (b) feel more satisfied with care received. Results of this study contribute to a better understanding of the role that health care providers play in individual and family adaptation to chronic conditions. © 1999 John Wiley & Sons, Inc. *Res Nurs Health* 22:357–368, 1999

Keywords: Down syndrome; family–provider relationships; well-being; disability

Children with Down syndrome and their families are faced with ongoing challenges that affect many aspects of their lives. In addition to having some degree of mental retardation, children with Down syndrome are susceptible to a wide range of health problems, including congenital heart disease, thyroid dysfunction, sleep apnea, frequent respiratory problems, and chronic ear infections (Cohen, 1995; Cooley, 1995). These health prob-

lems may result in activity restrictions, absences from school, frequent hospitalizations, and a reduced life expectancy (Cunningham, 1996). Challenges experienced by family members include increased demands on their time, energy, and resources, as well as dramatic shifts in their enactment of social roles (Barnett & Boyce, 1995; Padeliaadu, 1998). Although societal attitudes toward individuals with Down syndrome have be-

The author acknowledges Karen F. Pridham, PhD, RN, Helen Denne Schulte Professor of Nursing, Professor of Family Medicine, and Carol D. Ryff, PhD, Department of Psychology, University of Wisconsin–Madison, for their support and guidance with this research. Thanks are extended to the parents who participated in this study.

Contract grant sponsor: National Research Service Award; contract grant number: NR06338.

Contract grant sponsor: Helen Denne Schulte Research Award, University of Wisconsin–Madison, College of Nursing.

^{*}Assistant Professor.

come more positive, many children with Down syndrome and their families experience a sense of stigma from friends, relatives, and the wider community (Herbert & Carpenter, 1994; Van Riper, Pridham, & Ryff, 1992).

Currently, there is a growing consensus that the multiple challenges associated with Down syndrome do not lead necessarily to negative consequences for families (Gath, 1990; Hornby, 1995; Scott, Atkinson, Minton, & Bowman, 1997; Van Riper, Ryff, & Pridham, 1992). It remains unclear, however, why some families of children with Down syndrome are resilient and thrive, while others remain vulnerable and some deteriorate. To date, researchers who have addressed this issue have focused primarily on characteristics of the chronic condition, the affected child, the primary caretaker, and more recently, the family system (e.g., Cahill & Glidden, 1996; Cheng & Tang, 1995; Floyd & Gallagher, 1997; Rodrigue, Morgan, & Geffken, 1992; Sloper, Knussen, Turner, & Cunningham, 1991).

Despite increased awareness that relationships with health care providers can alter the experience of living with a chronic condition (see Faux & Knafl, 1996 for an excellent review of this literature) relatively little is known about how families with children who have Down syndrome appraise and respond to the ongoing relationships they develop with health care providers. Generally, researchers have treated the health-care staff as a static entity in the world of illness and disability (Chesler & Barbarin, 1987). Few researchers have viewed the family-provider relationship as a challenging one, or looked at health care providers as having an independent impact on well-being in families with children who have Down syndrome.

The purpose of this study was twofold: (a) to describe parental perceptions of family-provider relationships, and (b) to explore links between parental perceptions of family-provider relationships and well-being in families with children who have Down syndrome. A family is defined as "two or more individuals who depend on one another for emotional, physical, and/or economic support. The members of the family are self-defined" (Hanson & Boyd, 1996, p. 6). Well-being includes six dimensions of individual psychological well-being (i.e., autonomy, environmental mastery, personal growth, purpose in life, positive relations with others, and self-acceptance) and family functioning. Family-provider relationships include relationships with individual health care providers (e.g., nurses and physicians) and re-

lationships with health care-organizations (e.g., hospitals and clinics). For a family-provider relationship to be viewed as family-centered, health care providers must acknowledge and respect the pivotal role of the family in the lives of children with chronic conditions (Shelton, Jeppson, & Johnson, 1987).

To date, much of what is known about family-provider relationships following the birth of a child with Down syndrome has been derived from anecdotal reports by parents (Berube, 1996; Cunningham, Morgan, & McGucken, 1984; Garwick, Patterson, Bennett, & Blum, 1995; Herbert & Carpenter, 1994; Pueschel, 1985; Van Riper, Pridham, & Ryff, 1992; Van Riper & Selder, 1989). Typically, parents have described critical incidents (e.g., initial awareness of the child's diagnosis) or health care situations in which they were either extremely satisfied or extremely dissatisfied with family-provider interactions. In addition, some parents have noted how these pivotal encounters influenced, in either a positive or negative direction, the experience of raising a child with Down syndrome. For example, in an earlier study (Van Riper, Pridham, & Ryff, 1992), one mother noted that the physician helped to set the tone for how she felt about her daughter and the experience of parenting a child with Down syndrome. She said,

The pediatrician entered the room and sat down with us, held our hands, and explained the best that he could what having such a child meant. He reassured us that this was a time for celebration, that she would make us happier than we could ever imagine and that the only thing that made her different was that one (lousy) chromosome. She would be able to do anything she wants (read, write, talk, walk, etc.), it might just take her a little longer than most. But give her time, you'll see. . . . After his talk with us, I didn't cry anymore. I no longer felt sorry for myself. (p. 29)

In contrast, another mother recalled,

The only choices the doctor gave me were (1) I would take him home and love him. (2) Put him in an institution. (3) Order them to cut off his food supply. . . . What no one told me and I desperately needed to hear, was that these children generate more love than is imaginable. I was scared to death of my baby. . . . For the first few months, I felt suicidal. (p. 30)

Although parental descriptions of outstanding health care encounters have added significantly to our understanding of family-provider relationships following the birth of a child with Down syndrome, they may not reflect the more typical or ordinary family-provider interactions. That is, they may not provide us with information about

how families with children who have Down syndrome appraise and respond to the kind of interactions that they routinely have with health care providers. Moreover, parental descriptions of outstanding health care encounters may not capture the ongoing, dynamic nature of the long-term or "chronic" relationships that usually develop between families and health care providers when a family member has a chronic condition (McDaniel, Hepworth, & Doherty, 1992; Thorne, 1993).

Although the nature of family-provider relationships is a critical aspect of any illness experience, it becomes even more important when the affected individual is a child and the child's condition is a chronic one (Leff & Walizer, 1992). Many families of children with chronic conditions have extensive and complex responsibilities for health and illness-related care (Bruce & Ritchie, 1997). Because of this, families of children with chronic conditions are particularly vulnerable to lack of support and perceived criticism from health care providers, especially if they perceive that health care providers are holding them accountable for their child's poor health outcomes (McDaniel et al., 1992). Differences in opinion about caregiving and decision-making roles that may be transitory and easily overlooked in acute conditions may solidify and become strong determinants of action when a child has a chronic condition (Chesler & Barbarian, 1984, 1987). Habitual differences in opinion may result in family members feeling undervalued, angry, confused, helpless, hopeless, resentful, uncertain, and dissatisfied (Larson, 1998; Robinson, 1985; Thorne, 1993). In her work on family-larger-systems relationships, Imber-Black (1991) noted that difficult family-provider relationships take a toll on normal development for family members and may contribute to burnout and cynicism.

Some families who become dissatisfied with family-provider relationships "go through the motions" of seeking help from health care providers with little expectation that anyone could or would provide meaningful help, whereas other families withdraw from involvement with health care providers (Thorne & Robinson, 1988). Withdrawal from involvement with health care providers may afford some protection for the self-esteem of family members, but unfortunately, it also deprives them of potential help (Davis, 1991). Through help-seeking, families can enhance their expertise in caring for a child with a chronic condition or compensate for their lack of expertise. In addition, positive help-seeking experiences can

foster personal growth and the development of individual and family strengths (Dunst & Trivette, 1996; Fogel, 1993).

The point of this descriptive study was to bring together a number of different theoretical perspectives to help explain reported differences in how families of children with Down syndrome appraise and respond to the ongoing relationships they develop with health care providers. Wellman's framework theory of mind (1988, 1992) provided the basic infrastructure for this study. Wellman developed the framework to explain and predict intentional action, action that people undertake for a reason. According to Wellman, beliefs and desires are the two most important internal determinants of intentional action. People behave the way they do because they believe that certain actions will bring about the outcomes they desire. Outcomes of intentional action typically give rise to feelings, such as feelings of satisfaction or feelings of dissatisfaction. In turn, feelings affect beliefs and desires.

Wellman (1988) noted that specific theories of mind need to be developed if researchers wish to explain how individuals appraise and respond to specific situations. For this research, Wellman's framework theory of mind has been expanded in two ways. First, the focus has been broadened to acknowledge that human mental functioning is socially shared, or more generally, socially situated (Lave, 1993; Resnick, 1993; Vygotsky, 1978; Wertsch, 1991). Parental beliefs, desires, feelings, and intentions concerning family-provider relationships are developed through social interaction. In addition, they are inherently situated in cultural, institutional, and historical contexts (Burkett, 1991; Kleinman, Eisenberg, & Good, 1978). Therefore, the beliefs, desires, feelings, and intentions concerning family-provider relationships that parents of children with Down syndrome develop will be influenced by (a) family-provider interactions prior to and following the child's birth, (b) cultural beliefs about individuals with Down syndrome, and (c) the current philosophy of care for individuals with Down syndrome. In addition, because each family is a unique social entity with its own worldview and its own perspective on health and illness, family members will probably agree on some or all of their beliefs, desires, feelings, and intentions concerning family-provider relationships (Helman, 1991; Reiss, 1981, 1989).

A second way that Wellman's framework theory of mind (1988, 1992) has been expanded is that the construct of working models (Bowlby, 1982; Bretherton, 1991; Pridham, 1993) has been in-

cluded. This construct has been included to help explain how the determinants of intentional action identified by Wellman (i.e., beliefs, desires, feelings, and intentions) are organized into goal-corrected behavioral systems (working models). Goal-corrected behavioral systems are characterized by the process used to achieve the specified condition or set-goal, not by their ability to reach a predictable or predefined outcome (Bowlby, 1982). In goal-corrected behavioral systems, a behavioral response is selected from a repertoire of responses. Then the response is corrected or modified, based on whatever discrepancy exists between current performance and the set-goal.

Bowlby (1973, 1980, 1989) proposed that in the course of interacting with the physical and personal world, individuals construct working models. These models are dynamic mental constructions of self, others, and relationships with others that guide how people appraise and respond to important others (Bretherton, 1991; Pridham, 1993). Evidence is mounting that parents of children with chronic conditions typically view health care providers, especially the affected child's primary health care provider, as important others (Dixon, 1996; Faux & Seideman, 1996; Knafl, Breitmayer, Gallo, & Zoeller, 1992; Robinson, 1996; Thorne & Robinson, 1988). Because of this view

of health care providers as important others, parents of children with chronic conditions are likely to construct working models of family-provider relationships. These models not only shape how parents and other family members appraise and respond to family-provider interactions, they also provide the foundation for consistency in how individual family members and family systems respond (Reiss, 1981, 1989).

In summary, a variety of theoretical perspectives were brought together to help explain reported differences in how families of children with Down syndrome appraise and respond to the ongoing relationships they develop with health care providers. Major study variables are depicted in Figure 1. Specific questions explored in this study were (a) How are the family-provider-relationship working model components (e.g., beliefs, desires, feelings, and intentions) related? (b) Are belief-desire discrepancies concerning family-provider relationships associated with feelings of satisfaction with care? (c) Which individual and family characteristics are associated with the psychological well-being of parents, parental depression, and family functioning? (d) Which working model components are associated with the psychological well-being of parents, parental depression, and family functioning?

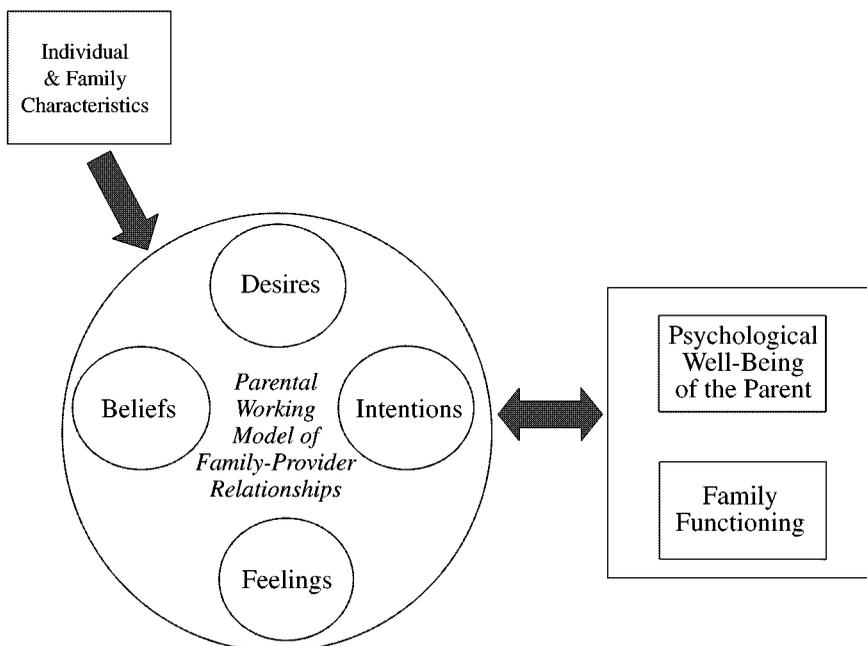


FIGURE 1. Major study variables: (a) individual and family characteristics, (b) parental working model components (beliefs about family-provider relationships, desires about family-provider relationships, feelings of satisfaction with care, and intentions regarding seeking help from health care providers), and (c) well-being variables (psychological well-being of the parent and family functioning).

METHOD

Sample

The sample for this descriptive, correlational study consisted of volunteer families that include an individual with Down syndrome. Approximately 130 families were invited to participate in this study. Families were recruited through Down syndrome support groups, study family referrals, and informational flyers distributed to the 35 families of children with Down syndrome listed in the Association for the Care of Children's Health *Parent Resource Directory* (Lawrence, Johnson, & Stepanek, 1994).

Of the 110 families (84.6% recruitment rate) who expressed interest in participating, 94 families (85.4% response rate) returned one or more questionnaires. Fifty-nine of the families returned one questionnaire (in all but two of these families, the mother was the parent who completed the questionnaire) and 35 families returned two questionnaires (both parents participated). There was no attempt made to obtain explanations for refusals to participate. Due to the relatively large difference in the number of mothers and fathers completing questionnaires, data from the 89 mothers are the focus of this report (three of the maternal questionnaires were missing too much data to be included). Data from fathers will be presented in a future paper.

The majority of mothers were white (95%), married (88%), and middle-class (58% had family incomes between \$25,000 to \$55,000). Mothers ranged in age from 26–65 years. The mean age of mothers at the birth of their child with Down syndrome was 31.64 ($SD = 5.72$). The mean years of education for mothers was 15.47 years ($SD = 2.20$). Thirty-seven percent ($n = 33$) of the mothers were employed outside of the home full time (30 or more hr per week), 34% ($n = 30$) were employed part time (less than 30 hr per week), and 29% ($n = 26$) were not employed outside of the home. Family size ranged from one child ($n = 8$) to 12 children ($n = 1$). The average number of children was three. The majority of families (over 87%) belonged to some type of organization for children with chronic conditions. Over 38% belonged to a local support group.

The average age of children with Down syndrome was 8.32 years. Over 48% ($n = 43$) of the children with Down syndrome were under the age of 7, 37% ($n = 33$) were 7–14 years, and under 15% ($n = 13$) were 14–22 years of age. While most of the children had been relatively healthy during the past year, 93% were reported to have

chronic health problems such as sleep apnea, a seizure disorder, or congenital heart disease. Forty percent missed more than 1 week of early intervention or school during the previous year due to health problems.

Measures

Family-provider relationships. The Family-Provider Relationships Instrument (FAMPRO), a self-report instrument consisting of three subscales (i.e., Beliefs-Desires, Feelings, Intentions) was developed by this investigator to assess four components (e.g., beliefs, desires, feelings, and intentions) of parents' working models of family-provider relationships. FAMPRO was developed following a review of the literature on family-provider relationships and family-centered care, and a reexamination of qualitative data collected in prior research concerning family-provider relationships following the birth of a child with Down syndrome (Van Riper, 1987; Van Riper, Pridham, & Ryff, 1992, Van Riper & Selder, 1989). FAMPRO was reviewed by a panel of experts for evidence of face validity. The panel of nine experts consisted of four nurses (three master's-prepared and one doctorally prepared) with expertise in maternal-child nursing, two primary care physicians, and three parents of children with Down syndrome. Changes recommended by these individuals were incorporated prior to data collection. For this sample, alpha coefficients for the subscales ranged from .83–.91. The subscales of FAMPRO are described briefly below (see Van Riper, 1995 for a more in-depth description).

For the belief-desire subscale, parents are asked to read 42 statements concerning family-provider relationships (e.g., Our child's primary health care provider acknowledges that we know, or are beginning to know, our child better than anyone else. Our family takes an active role in planning the care our child with Down syndrome receives.). After reading each statement, the parents are asked to indicate on a 4-point scale the extent to which they agree that the statement reflects their family's current relationship with the affected child's primary health care provider. Then, parents are asked to indicate on a 4-point scale the extent to which they want their family's relationship with the identified provider to be like the one portrayed by the statement. The beliefs score is an indicator of the nature of the current family-provider relationship, while the desires score is an indicator of the family's "ideal" or desired family-provider relationship. Possible scores for each scale range from 42–168, with higher scores indi-

cating positive, family-centered relationships. The belief–desire discrepancy score is an indicator of “goodness of fit” between the type of relationship families want with health care providers and the type of relationship they have. Discrepancies are calculated for each item, then totaled. Possible scores range from 0–126, with lower scores indicating a better fit or less discrepancy.

The feelings subscale was developed to assess how satisfied parents are with 16 different aspects of care (e.g., accessibility of care, ability of provider to communicate effectively with family members) and how important these aspects of care are to parents. The feelings of satisfaction with care score is calculated using an approach similar to the one used by Ferrans and Powers (1985) to calculate quality-of-life scores. Satisfaction responses are adjusted to take into account the importance responses. Possible scores range from 0–30. Higher scores indicate greater satisfaction.

The intentions subscale is a modification of the Willingness to Seek Help measure developed by Nadler, Lewinstein, and Rahav (1991). Parents are presented with 15 situations (the original measure had seven situations) in which the parent of a child with Down syndrome might need outside help (e.g., child develops an unexpected health problem, one or more family members are feeling exhausted or “burnt out”). For each situation, parents are asked to indicate on a 5-point scale how likely it would be that their family would (a) try to deal with the situation themselves, (b) ask for help from friends and relatives, (c) ask for help from other parents of children with Down syndrome, (d) ask for help from health care providers, and (e) ask for help from other professionals. Parents’ responses are summed to obtain five help-seeking scores (e.g., self-help, help-seeking from close others, help-seeking from similar others, help-seeking from health care providers, help-seeking from other professionals). For this study, the help-seeking from health care providers score was used to assess intentions regarding seeking help from health care providers. Possible scores range from 15–75, with higher scores indicating greater intention to seek help.

Parental psychological well-being. Ryff’s (1989) measure of psychological well-being was used to assess the psychological well-being of parents. It consists of six dimensions: autonomy, environmental mastery, personal growth, purpose in life, positive relations with others, and self acceptance. Each dimension includes 14 items rated on a 6-point scale, with possible scores ranging from 0–84 for the individual scales and higher scores indicating more positive well-being. According to Ryff, alpha coefficients for the individual scales

have ranged from .83–.91. Convergent and discriminant validity tests revealed that the six scales correlate in a positive manner with prior measures of positive functioning and in a negative manner with measures of negative functioning. Confirmatory factor analyses with data from a nationally representative sample (Ryff & Keyes, 1995) provided support for the six-factor model of psychological well-being originally proposed by Ryff, as well as a single second-order super factor (psychological well-being). Alpha coefficients for the present sample ranged from .82 (personal growth scale) to .92 (self-acceptance scale).

Parental depression. The Center for Epidemiological Studies Depression Scale (CES-D) (Radloff, 1977) was used to tap symptoms of parental depression, a negative aspect of psychological functioning. This scale consists of 20 items (e.g., I felt that everything I did was an effort). Parents were asked to rate on a 4-point scale the extent to which each statement applied to them during the past week. Possible scores range from 0–60. Scores greater than 16 are considered to suggest increased risk for clinical depression. Radloff reported data demonstrating acceptable test-retest reliability, good concurrent validity with other self-report measures of depression, and good discriminant validity. Alpha coefficients were reported as .85 for community samples and .90 for clinical samples. The alpha coefficient for the present sample was .86.

Family functioning. The General Scale of the Family Assessment Measure (FAM III), a self-report measure developed from the process model of family functioning (Skinner, Steinhauer, & Santa-Barbara, 1983) was used to assess family functioning. The General Scale of FAM III (50 items) focuses on the family as a system. It provides an overall rating of family functioning. According to Skinner et al. (1983), the majority of standardized scores for “normal” families fall between 40 and 60. Standardized scores outside this range are thought to indicate either very healthy functioning (40 or below) or considerable disturbance (60 or above). The alpha coefficient for the General Scale was reported as .93. For the present sample, the alpha coefficient was .84. With regard to validity, the General Scale has significantly differentiated between “normal” families and clinical families (Skinner, 1987).

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 containing an introductory letter, one or two questionnaires depending on how many parents signed the consent, and a prestamped return envelope for each questionnaire. Parents were asked to return the completed questionnaires within 2 weeks. Based on pilot testing, the questionnaire took approximately 1 to 2 hr to complete. Follow-up postcard reminders were sent to nonrespondents after 3 weeks. Telephone calls were made to those parents who had not responded to the postcard reminders after 1 week.

RESULTS

Descriptive statistics were computed for all the scales used in the study. Means, standard deviations, and actual ranges for the major study variables are shown in Table 1. Scores for the beliefs, belief-desire discrepancy, and feelings of satisfaction with care subscales of FAMPRO indicate that, in general, these mothers are satisfied with the care received, and they believe that their families have developed positive relationships with providers. An interesting finding was that a number of mothers indicated that family members had "worked hard" to achieve the kind of relationship they had with providers. The mean score for the desires subscale ($M = 140.15$, $SD = 12.19$) indicates that mothers in this sample wanted family-provider relationships that reflected key elements of family-centered care (Shelton et al., 1987). Scores for the well-being variables reflect positive parental and family functioning. The mean depression score for this sample ($M = 9.82$, $SD =$

9.59) fell well below 16, the score indicative of clinical depression (Radloff, 1977). Also the mean level of family functioning ($M = 48.01$, $SD = 6.96$) was lower, suggesting better functioning, than the mean ($M = 50.00$) for the normative sample (Skinner et al., 1983).

Correlational Analysis

Results from the descriptive statistics and bivariate scatterplots indicated that the assumptions required for correlational analysis (e.g., evidence of a normal distribution, approximately equal variability, linear relationships between variables) were met. Therefore, a correlation matrix was generated for the major study variables and specific individual and family characteristics. Examination of the correlation matrix revealed that only two of the individual and family characteristics (e.g., maternal age and family income) were significantly associated ($p < .05$) with one or more of the well-being variables. Correlations among maternal age, family income and the major study variables are summarized in Table 2.

Associations between working model components. Beliefs were significantly associated with the other three working model components: desires ($r = .71$, $p < .01$), feelings ($r = .43$, $p < .01$), and intentions ($r = .37$, $p < .01$) (Table 2). There was also a significant association between desires and intentions ($r = .22$, $p < .05$). Mothers who depicted family-provider relationships as positive and family-centered reported more satisfaction with care and greater intentions to seek help from health care providers.

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

	<i>M</i>	<i>SD</i>	Actual Range
Beliefs ($n = 86$)	132.63	13.67	96-162
Desires ($n = 86$)	140.15	12.19	110-162
Belief-desire dependency ($n = 86$)	10.16	10.37	0-47
Feelings ($n = 89$)	24.77	4.18	9-30
Intentions ($n = 86$)	42.47	11.90	21-70
Family functioning ($n = 85$)	48.01	6.96	32-60
Depression ($n = 89$)	9.82	9.59	0-48
Overall psychological well-being ($n = 88$)	388.45	44.30	220-465
Autonomy	62.67	8.95	39-84
Environmental mastery	59.39	9.06	32-78
Personal growth	69.26	7.29	52-83
Positive relations with others	66.48	9.68	33-83
Purpose in life	66.73	8.59	35-83
Self-acceptance	63.89	10.46	23-83

Note. For family functioning, M of normative sample = 50, $SD = 10$; 40 or below = very healthy functioning; 60 or above = considerable disturbance in functioning.

Table 2. Correlations Among Maternal Age, Family Income, and Major Study Variables

	1	2	3	4	5	6	7	8	9	10
1. Maternal age	1.00									
2. Family income	-.05	1.00								
3. Beliefs about FPR	.04	.30**	1.00							
4. Desires about FPR	.14	.15	.71**	1.00						
5. Belief–desire discrepancy	.13	-.15	-.51**	.11	1.00					
6. Feelings of satisfaction	-.10	.20	.43**	.03	-.56**	1.00				
7. Intentions to seek help	-.04	.13	.37**	.22*	-.18	.05	1.00			
8. Family functioning	.02	-.12	-.36**	-.32**	.22*	-.24*	.07	1.00		
9. Depression	.34**	-.21*	-.18	-.15	-.12	-.26*	.15	.37**	1.00	
10. Overall psychological well-being	-.19	.33**	.28**	.25*	-.11	.26*	-.08	-.55**	-.61	1.00

Note. FPR = Family–Provider Relationship; HCP = Health Care Provider.

* $p \leq .05$. ** $p \leq .01$.

Association of belief–desire discrepancy with feelings of satisfaction with care. Findings in Table 2 reveal a significant inverse relationship between belief–desire discrepancy and feelings of satisfaction with care ($r = -.51, p < .01$). Mothers who reported less discrepancy between what their family’s relationship with health care providers was like and what they wanted the relationship to be like reported more satisfaction with care.

Individual and family characteristics associated with well-being variables. Family income was significantly inversely associated with parental depression ($r = -.21, p < .05$) and positively associated with overall parental psychological well-being ($r = .33, p < .01$) (Table 2). Additional bivariate correlations revealed a significant positive association between family income and all six dimensions of psychological well-being: autonomy ($r = .21, p < .05$), environmental mastery ($r = .32, p < .01$), personal growth ($r = .23, p < .05$), purpose in life ($r = .24, p < .05$), positive relations with others ($r = .33, p < .01$), and self acceptance ($r = .29, p < .01$). Mothers who reported higher family incomes reported lower levels of depression and higher levels of psychological well-being. There was also a significant positive association between current age of the mother and maternal depression ($r = .34, p < .01$). Depression scores tended to be higher for older mothers.

Associations between working model components and well-being variables. The feelings component was significantly associated with all three well-being variables: family functioning ($r = -.24, p < .05$), overall psychological well-being ($r = .26, p < .05$), and parental depression ($r = -.26, p < .05$) (Table 2). The beliefs and desires components were significantly associated with family functioning ($r = -.36, p < .01, r = -.32, p < .01$, respectively) and overall psychological well-being ($r = .28, p < .01, r = .25, p < .05$, respectively), but not with depression. These patterns of bivariate correlations indicate that mothers who wanted, and believed that they had, positive family-centered relationships with providers and who reported increased feelings of satisfaction with care had higher levels of psychological well-being and family functioning. Also, mothers who reported increased feelings of satisfaction with care reported lower levels of depression. Partial correlations revealed that all of the significant associations noted above remained significant after controlling for family income and maternal age.

Additional bivariate correlations revealed significant associations between beliefs and four dimensions of psychological well-being: autonomy ($r = .28, p < .01$), environmental mastery ($r = .24, p < .05$), purpose in life ($r = .29, p < .01$), and positive relations with others ($r = .26, p < .05$). There were also significant associations between feelings and three dimensions of psychological well-being: environmental mastery ($r = .26, p < .05$), positive relations with others ($r = .25, p < .05$), and self-acceptance ($r = .24, p < .05$). In addition, desires was significantly associated with purpose in life ($r = .26, p < .05$).

DISCUSSION

When mothers of children with Down syndrome believed that their family’s relationship with health care providers was positive and family-centered, they felt more satisfied with the care that their child was receiving and they were more likely to seek help from health care providers. In ad-

dition, when a discrepancy existed between what mothers wanted the family-provider relationship to be like and what they believed the relationship was like, mothers were less satisfied with the care received. Finally, higher levels of individual and family well-being were reported by mothers who (a) wanted, and believed they had, positive family-centered relationships with providers, and (b) were more satisfied with care received.

Although the philosophy and principles of family-centered care are frequently cited in the literature, there is growing recognition that for many families, family-centered care is more of a dream than a reality (Ahmann, 1994; Bruce & Ritchie, 1997; Dunst & Trivette, 1996; Garwick, Kohrman, Wolman, & Blum, 1998). Results from this study support the findings by Diehl, Moffitt, and Wade (1991) that most parents want family-centered care. An encouraging finding from the current study is that the majority of the mothers in this study reported that their family's relationship with their child's primary health care provider had some or all of the critical elements of family-centered care (e.g., families are recognized as the constant in the child's life, families are supported in their natural caregiving and decision-making roles). Further research is needed to delineate how families obtain family-centered care. Do they just get lucky and pick a provider that believes in family-centered care? Or, is it primarily through their own efforts? How does the family-provider relationship develop over time? What individual and family resources are needed to develop a positive family-centered relationship with health care providers?

Findings from this study strengthen the findings from earlier studies concerning health care relationships in a number of ways. First, in earlier studies, parents were typically asked to describe critical incidents or outstanding encounters with health care providers. In the current study, parents were asked to share their beliefs about typical, as well as outstanding, encounters with providers. This may provide a more accurate picture of the ongoing relationships families develop with health care providers. It may also further our understanding of which kind of encounters (e.g., typical or outstanding, positive or negative) have the greatest impact on feelings of satisfaction with care.

Another way that findings from this study strengthen the findings from prior work is that in the earlier studies parents were seldom asked to respond to questions about family-provider interactions in terms of their feelings of overall satisfaction with care. In the current study, a quantitative,

self-report measure was used to assess parental feelings of overall satisfaction with care. This measure takes into account both satisfaction with, and importance of, various aspects of care. Also, parents were encouraged to comment on their overall satisfaction with care. Comments by mothers in this study were very similar to those reported by Knafl et al. (1992).

This study is one of the first to explore links between family-provider relationships and well-being in families that include a child with a chronic condition. The finding that mothers who (a) wanted, and believed they had, positive family-centered relationships with providers, and (b) felt more satisfied with care received reported higher levels of psychological well-being and family functioning strengthens the argument for family-centered care. It also provides support for the view that health care relationships can be both a resource and a constraint (Chesler & Barbarin, 1984; 1987; Ray & Ritchie, 1993; Thorne, 1993). When health care relationships have some or all of the essential elements of family-centered care, family members can grow and develop through these relationships (Fogel, 1993). In contrast, when health care relationships are adversarial, individual and family well-being may be adversely affected (Robinson, 1985). Disrespectful behavior by health care providers is likely to threaten a parent's psychological well-being, especially if the parent construes the health care provider as being of a high status, having prestige, an expert, and therefore, an important source of help (Davis, 1991).

The significance of family-provider relationships may vary across the life course of the affected individual and their family. For example, during the first few months after the birth of a child with Down syndrome, a relationship with health care providers that is effective and mutually satisfying may be viewed as critical. A large belief-desire discrepancy concerning the family-provider relationship may result in parents looking for a new health care provider for their child. In contrast, when the child's health status is fairly stable and parents have come to terms with the fact that their child is "other than expected," a large belief-desire discrepancy may not be viewed as that important. Sloper and Turner (1992) noted that as the age of the child with Down syndrome increases, parents have fewer contacts with health care providers and there is a reduction in the number of times parents seek help from health care providers. Although this finding might suggest that families with older children who have Down syndrome have fewer health care needs, another possibility is that the child's

parents have become very skilled in meeting their child's special health care needs. A third possibility is that previous attempts to seek help from health care professionals have been so unsatisfactory that parents avoid seeking help from health care providers. Further research is needed on the help-seeking patterns of parents who have children with chronic conditions.

Several limitations in this research should be noted. First, the sample consisted of volunteers. Parents who participated in this study were for the most part reasonably well-educated, belonged to a support group or an organization for families of children with special health care needs, and were motivated to participate in research. Sample characteristics such as these warrant caution in any attempt to generalize the findings beyond the study sample.

A second limitation is that, despite efforts to obtain data from both mothers and fathers, only 37 fathers returned completed questionnaires. One father noted that he could not complete the questionnaire because he was not the one who "deals with health care providers." Another father indicated that he would be glad to participate in the study, but he "wasn't going to do the essay part" (i.e., the open-ended questions). Failure to obtain completed data sets from both parents for the majority of families in this study limited the extent to which within-family comparisons of parental working models could be made. In addition, limited participation by fathers resulted in the focus of this report being restricted to maternal perceptions of family-provider relationships. A growing number of fathers are actively involved in the ongoing health care of children with Down syndrome. Therefore, it is essential that their voices be heard. Future studies concerning family-provider relationships must include creative approaches to recruit and retain fathers in the research.

A third limitation of this study is that it was a cross-sectional study. A longitudinal study needs to be conducted to examine how parents of children with Down syndrome construct or revise their working models of family-provider relationships following the birth of a child with Down syndrome. Also, a longitudinal study is needed to sort out the direction of the effects. Mothers with higher levels of psychological well-being may be more effective in developing positive relationships with health care providers. Therefore, the effects are most likely multidirectional.

Overall, the findings of this study indicate that relationships with health care providers can influence the experience of raising a child with Down

syndrome. Family-provider relationships that are characterized as positive and family-centered are associated with increased satisfaction with care, greater willingness to seek help from providers, and higher levels of individual and family well-being. When a discrepancy exists between what mothers want their family's relationship with providers to be like and what they believe it is like, mothers feel less satisfied with the care that their child with Down syndrome is receiving. The following quote from a mother of a 1-year-old with Down syndrome captures the major findings of this study: "The attitude and competency of our pediatrician have made such a wonderful difference in our lives, even though we'd like her office to be closer, it's [the extra travel] worth it to us. . . . Having a health care provider who works with us, listens to our concerns, and doesn't dismiss them, has made us a *happier* family."

REFERENCES

- Ahmann, E. (1994). Family-centered care: Shifting orientation. *Pediatric Nursing*, 20, 113–116.
- Barnett, W.S., & Boyce, G.C. (1995). Effects of children with Down syndrome on parent's activities. *American Journal of Mental Retardation*, 100, 115–127.
- Berube, M. (1996). *Life as we know it: A Father, a family, and an exceptional child*. New York: Pantheon Books.
- Bowlby, J. (1973). *Attachment and loss, Vol. 2: Separation*. New York: Basic Books.
- Bowlby, J. (1980). *Attachment and loss, Vol. 3: Loss, sadness, and depression*. New York: Basic Books.
- Bowlby, J. (1982). *Attachment and loss, Vol. 1 (2nd ed.)*. New York: Basic Books.
- Bowlby, J. (1989). The role of attachment in personality development and psychopathology. In S.I. Greenspan & G.H. Pollock (Eds.), *The course of life. Vol. 1: Infancy* (pp. 229–270). Madison, CT: International Universities Press.
- Bretherton, I. (1991). Pouring new wine into old bottles: The social self as internal working model. In M.R. Gunnar & L.A. Stroufe (Eds.), *Self Processes and Development: The Minnesota Symposia on Child Development* (Vol. 23, pp. 1–41). Hillsdale, NJ: Erlbaum.
- Bruce, B., & Ritchie, J. (1997). Nurses' practices and perceptions of family-centered care. *Journal of Pediatric Nursing*, 12, 214–222.
- Burkett, G. (1991). Culture, illness, and the biopsychosocial model. *Family Medicine*, 23, 287–290.
- Cahill B.M., & Glidden, L.M. (1996). Influence of child diagnosis on family and parental functioning: Down syndrome vs other disabilities. *American Journal of Mental Retardation*, 101, 149–160.
- Cheng, P., & Tang, C.S. (1995). Coping and psychological distress of Chinese parents of children with

- Down syndrome. *Mental Retardation*, 33 (10), 10–20.
- Chesler, M., & Barbarin, O. (1984). Relating to the medical staff: How parents of children with cancer see the issues. *Health and Social Work*, 9, 49–65.
- Chesler, M., & Barbarin, O. (1987). Childhood cancer and the family. New York: Brunner/Mazel, Inc.
- Cohen, W.I. (1995). Health care in the neonatal period and infancy. In D. Refern (Ed.), *Caring for individuals with Down syndrome and their families*. (pp. 14–26). Columbus, OH: Ross Products Division, Abbott Laboratories.
- Cooley, W.C. (1995). Preventive health care for children with Down syndrome. In D.C. Van Dyke, P. Mattheis, S.S. Eberly, & J. Williams (Eds.), *Medical and surgical care for children with Down Syndrome: A guide for parents*. (pp. 15–33). Bethesda, MD: Woodbine House.
- Cunningham, C. (1996). *Understanding Down Syndrome: An introduction for parents*. Cambridge, MA: Brookline Books.
- Cunningham, C., Morgan, P., & McGucken, R. (1984). Down syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology*, 26, 33–39.
- Davis, H. (1991). Counseling families of children with disabilities. In H. Davis & L. Fallowfield (Eds.), *Counseling and communication in health care*. (pp. 223–237). New York: Wiley.
- Diehl, S., Moffitt, K., & Wade, S. (1991). Focus group interview with parents of children with medically complex needs: An intimate look at their perceptions and feelings. *Children's Health Care*, 20, 170–178.
- Dixon, D. (1996). Unifying concepts in parents' experiences with health care providers. *Journal of Family Nursing*, 2, 111–132.
- Dunst, C.J., Trivette, C.M. (1996). Empowerment, effective help-giving practices and family-centered care. *Pediatric Nursing*, 22, 334–338.
- Faux, S.A., & Knafl, K.A. (1996). Special issue: Relationships between health care providers and families. *Journal of Family Nursing*, 2, 107–204.
- Faux, S.A., & Seideman, R.Y. (1996). Health care professionals and their relationships with families who have members with developmental disabilities. *Journal of Family Nursing*, 2, 217–238.
- Ferrans, C., & Powers, M. (1985). Quality of life index: Development and psychometric properties. *ANS: Advances in Nursing Science*, 8(1), 15–24.
- Floyd, F.J., & Gallagher, E.M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, 46, 359–371.
- Fogel, A. (1993). *Developing through relationships*. Chicago, IL: University of Chicago Press.
- Garwick, A.W., Kohrman, C., Wolman, C., & Blum, R.W. (1998). Families' recommendations for improving services for children with chronic conditions. *Archives of Pediatric and Adolescent Medicine*, 152, 440–448.
- Garwick, A.W., Patterson, J., Bennett, F.C., & Blum, R.W. (1995). How families first learn about their child's chronic condition. *Archives of Pediatric and Adolescent Medicine*, 149, 991–997.
- Gath, A. (1990). Down syndrome children and their families. *American Journal of Medical Genetics Supplement*, 7, 314–317.
- Hanson, S., & Boyd, S. (1996). Family nursing: An overview. In S. Hanson & S. Boyd (Eds.), *Family health care nursing: Theory, practice, and research* (pp. 6–34). Philadelphia: F.A. Davis.
- Helman, C.G. (1991). The family culture: A useful concept for family practice. *Family Medicine*, 23, 376–381.
- Herbert, E., & Carpenter, B. (1994). Fathers-the secondary partners: Professional perceptions and fathers' reflections. *Children & Society*, 8, 31–41.
- Hornby, G. (1995). Fathers' views of the effects on their families of children with Down syndrome. *Journal of Child and Family Studies*, 4, 103–117.
- Imber-Black, E. (1991). A family-larger-system perspective. *Family Systems Medicine*, 9, 371–395.
- Kleinman, A., Eisenberg, L., & Good, B. (1978). Culture, illness, and care: Clinical lessons from anthropologic and cross-cultural research. *Annals of Internal Medicine*, 88, 251–258.
- Knafl, K., Breitmayer, B., Gallo, A., & Zoeller, L. (1992). Parents' views of health care providers: An exploration of the components of a positive working relationship. *Children's Health Care*, 21, 90–95.
- Larson, E. (1998). Reframing the meaning of disability to families: The embrace of paradox. *Social Science and Medicine*, 47, 865–875.
- Lave, J. (1993). Situating learning in communities of practice. In L.B. Resnick, J.M. Levine, & D. Teasley (Eds.), *Perspectives on socially shared cognition* (pp. 63–84). Washington, D.C.: American Psychological Association.
- Lawrence, K., Johnson, G., & Stepanek, J. (1994). 1994 parent resource directory. Bethesda, MD: Association for the Care of Children's Health.
- Leff, P., & Walizer, E. (1992). *Building the healing partnership: Parents, professionals, and children with chronic illnesses and disabilities*. New York: Brookline.
- McDaniel, S.H., Hepworth, J., & Doherty, W.J. (1992). *Medical Family therapy: A biopsychosocial approach to families with health problems*. New York: Basic Books.
- Nadler, A., Lewinstein, E., & Rahav, G. (1991). Acceptance of mental retardation and help-seeking by mothers and fathers of children with mental retardation. *Mental Retardation*, 29, 17–23.
- Padeliadu, S. (1998). Time demands and stress in Greek mothers of children with Down syndrome. *Journal of Intellectual Disability Research*, 42, 144–153.
- Pridham, K. (1993). Anticipatory guidance of parents of new infants: Potential contribution of the internal working model construct. *Image: Journal of Nursing Scholarship*, 25, 49–56.
- Pueschel, S.M. (1985). Changes of counseling practices at the birth of a child with Down syndrome. *Applied Research in Mental Retardation*, 6, 99–108.

- Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement*, 1, 385–400.
- Ray, L.D., & Ritchie, J.A., (1993). Chronic illness and parental coping. *Journal of Pediatric Nursing*, 8, 217–225.
- Reiss, D. (1981). *The family's construction of reality*. Cambridge, MA: Harvard University Press.
- Reiss, D. (1989). The represented and practicing family: Contrasting visions of family continuity. In A.J. Sameroff & R.N. Emde (Eds.), *Relationship disturbances in early childhood: A developmental approach* (pp. 191–220). New York: Basic Books.
- Resnick, L.B. (1993). Shared cognition: Thinking as social practice. In L.B. Resnick, J.M. Levine, & D. Teasley (Eds.), *Perspectives on socially shared cognition* (pp. 1–22). Washington, D.C.: American Psychological Association.
- Robinson, C. (1985). Parents of hospitalized chronically ill children: Competency in question. *Nursing Papers*, 17, 59–65.
- Robinson, C. (1996). Health care relationships revisited. *Journal of Family Nursing*, 2, 152–173.
- Rodrigue, J.R., Morgan, S.B., & Geffken, G.R. (1992). Psychosocial adaptation of fathers of children with autism, Down syndrome, and normal development. *Journal of Autism and Developmental Disorders*, 22, 249–263.
- Ryff, C.D. (1989). Happiness is everything, or is it? Explorations on the meaning of psychological well-being. *Journal of Personality and Social Psychology*, 57, 1069–1081.
- Ryff, C.D., & Keyes, C.L. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, 69, 719–727.
- Scott, B.S., Atkinson, L., Minton, H.L., & Bowman, T. (1997). Psychological distress of parents of infants with Down syndrome. *American Journal on Mental Retardation*, 102, 161–171.
- Shelton, T.L., Jeppson, E.S., & Johnson, B.H. (1987). *Family-centered care for children with special health care needs*. Bethesda, MD: Association for the Care of Children's Health.
- Skinner, H. (1987). Self-report instruments for family assessment. In T. Jacob (Ed.), *Family interaction and psychopathology: Theories, methods, and findings* (pp. 427–453). New York: Plenum Press.
- Skinner, H., Steinhauer, P.D., & Santa-Barbara, J. (1983). The Family Assessment Measure. *Canadian Journal of Community Mental Health*, 2, 91–105.
- Sloper, P., Knussen, C., Turner, S., & Cunningham, C. (1991). Factors related to stress and satisfaction with life in families of children with Down syndrome. *Journal of Child Psychology and Psychiatry*, 32, 655–676.
- Sloper, P., & Turner, S. (1992). Service needs of families of children with severe physical disability. *Child: Care, Health and Development*, 18, 259–282.
- Thorne, S. (1993). *Negotiating health care: The social context of chronic illness*. Newbury Park, CA: Sage.
- Thorne, S., & Robinson, C. (1988). Health care relationships: The chronic illness perspective. *Research in Nursing & Health*, 11, 293–300.
- Van Riper, M. (1987). *Life transition: Parental responses following the birth of an infant*. Unpublished master's thesis. University of Wisconsin-Milwaukee School of Nursing.
- Van Riper, M. (1995). *Links between family-provider relationships and well-being in families with children who have Down syndrome working models of family-provider relationships*. Unpublished doctoral dissertation. University of Wisconsin-Madison.
- Van Riper, M., Pridham, K., & Ryff, C. (1992). Symbolic interactionism: A perspective for understanding parent-nurse interactions following the birth of a child with Down syndrome. *Maternal Child Nursing Journal*, 20, 21–40.
- Van Riper, M., Ryff, C., & Pridham, K. (1992). Parental and family well-being in families of children with Down syndrome: A comparative study. *Research in Nursing & Health*, 15, 227–235.
- Van Riper, M., & Selder, F. (1989). Parental responses to the birth of a child with Down syndrome. In J. Rainer et al. (Eds.), *Genetic disease: The unwanted inheritance* (pp. 59–76). New York: Haworth Press.
- Vygotsky, L.S. (1978). *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press.
- Wellman, H.M. (1988). First steps in the child's theorizing about the mind. In J. Astington, P. Harris, & D. Olson (Eds.), *Developing theories of mind* (pp. 64–92). New York: Cambridge University Press.
- Wellman, H.M. (1992). *The child's theory of mind*. Cambridge, MA: MIT Press/Bradford Books.
- Wertsch, J.V. (1991). *Voices of the mind: A sociocultural approach to mediated action*. Cambridge, MA: Harvard University Press.