

# **Relationships Between Stress, Coping Resources, and Satisfaction with Family Functioning in Families of Children with Disabilities**

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L'objectif de cette étude descriptive de corrélation est d'examiner les liens entre le stress, les ressources de soutien et la satisfaction quant au fonctionnement de la famille chez les familles qui s'occupent à domicile d'enfants souffrant de retards de développement. L'enquête portait sur cinquante familles qui ont utilisé les services d'un programme de soins de relève afin d'étudier les relations entre les caractéristiques des enfants (problèmes de comportement et situations handicapantes), les ressources de soutien (la maîtrise de la situation et la santé, l'estime et la communication, la tolérance de la famille et le soutien social), et la variable principale de l'intérêt portait sur la satisfaction quant au fonctionnement de la famille. Les conclusions énoncent que les familles qui ont des enfants souffrant de retards de développement connaissent des facteurs d'agressions importants en termes de situations handicapantes et de gravité des problèmes de comportement de leur enfant. Elles mentionnent cependant des ressources de soutien satisfaisantes, à savoir la maîtrise de la situation, la santé, la tolérance, l'estime et la communication. Bien que les pointages de soutien social soient moins élevés que les pointages normatifs, les pointages de soutien social pour les conjoints et les amis prédisaient de façon significative la satisfaction quant au fonctionnement de la famille. On étudie les conséquences par rapport aux praticiens.

The purpose of the current descriptive correlational study was to examine relations between stress, coping resources, and satisfaction with family functioning in families caring for children with developmental disabilities at home. Fifty families who used the services of a respite care program were surveyed to examine relationships among child characteristics (behavioral problems and handicapping conditions); coping resources including mastery and health, esteem and communication, family hardiness, and social support; and the primary outcome variable of satisfaction with family functioning. Families of children with developmental disabilities experience significant stressors in terms of the severity of their child's handicapping conditions and behaviour problems. However, they reported satisfactory coping resources such as mastery and health, hardiness, and esteem and communication. Although they were lower than normative scores, social support scores for spouses and friends were related to satisfaction with family functioning. Implications for practitioners are discussed.

As health care policy mandates that increasing numbers of children with developmental disabilities be cared for in the community, the impact of expanding families' responsibility for long-term caregiving is not well understood. Further, factors that enable family caregivers to manage their child's

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care effectively at home are not clearly evident, but one of the factors they identify as essential is the availability and use of respite care. Although it is limited, research on the effects of respite care suggests that it is beneficial to families of handicapped children (Botuck & Winsberg, 1991). Halpern (1985) reported that respite care positively affected family functioning, but that study focused primarily on preservation of family stability. The current study will examine child characteristics and parental coping resources to determine which factors are most significant in predicting satisfaction with family functioning.

Families caring for sons and daughters with disabilities at home have been found to experience a number of stressors. Behaviour problems and the presence of multiple conditions add to the stress experienced by families (Cameron, Armstrong-Stassen, Orr & Loukas, 1991; Quine & Pahl, 1985). Furthermore, alleviation of behaviour problems may be difficult, especially when neurological deficits make the behaviour difficult if not impossible to change. In addition, a multiplicity of handicaps often result in significant, long-term dependence of the child on the parent for caregiving needs that range from basic to complex. Consequently, the overall stress experienced by parents may become significant and can affect family functioning (Crnic, Friedrich, & Greenberg, 1983; Fewell, 1986; Power & Dell Orto, 1980).

A wide body of literature has examined coping resources and their links to stress. Lazarus and Folkman (1984) identified a number of resources that may assist individuals in dealing with stress, including health and energy, problem-solving skills, perceptions of situations, family relationships, and social support. Many studies have revealed the importance of the family's support system and coping resources (Kirkham, Schilling, Norelius, & Schinke, 1986; Wilcox & Vernberg, 1985; Young, 1981). In studies of families of children with mental handicaps, mothers' coping resources were found to influence the stress they experienced. Friedrich, Wilturner, & Cohen, (1985) found that marital satisfaction, maternal depression, locus of control, and quality of family social climate all predicted maternal stress. McCubbin and Comeau (1987) reported that the family resources of esteem/communication and mastery/health were negatively related to family conflict. Further, these two resources were positively related to child health outcomes (McCubbin, 1988). Failla and Jones (1991) found that family hardiness, functional support, family stressors and parental age accounted for significant differences in satisfaction with family functioning in families caring for young children with developmental disabilities. Frey, Greenberg, and Fewell (1989) found that the family social support network and problem-solving abilities contributed to positive outcomes for parents of young children with handicaps. Based on several studies, Dunst, Trivette, Gordon, and Pletcher (1989) posited that social support is very important to families caring for handicapped children, and reported several benefits including positive family interactions and child outcomes.

Some families with children with handicaps may have access to social support in the form of respite care. Respite services are designed to provide parents with temporary relief from caregiving demands, maintain family integrity, and reduce institutionalization of handicapped individuals (Schwartz, 1993). Parents sometimes turn to friends or relatives for respite care, but they often lack the skills necessary to care for handicapped children, so parents turn to professional respite services (Gafford, 1987). Studies of the effects of respite care suggest it may relieve parents' depression and stress, increase their sense of well-being, improve their attitude toward and relations with the handicapped child, and provide more free time for work, social or leisure activities (Botuck & Winsberg, 1991; Halpern, 1985; Marc & MacDonald, 1988; Rimmerman, 1989).

Parents of children with disabilities experience high levels of stress relative to the multiplicity of their child's handicapping conditions and problem behaviours, which may in turn affect family functioning. Coping resources may also influence parental stress and family functioning, but the specific relations among these variables are unclear. More specifically, the influence of internal versus external coping resources on parents' ability to manage their child's care effectively and preserve family functioning needs to be examined.

### ***Purpose and Research Questions***

Thus, the purpose of this study was to examine stressors, (child conditions and behaviours), internal (hardiness, mastery/health, esteem/communication) and external (social support) coping resources, and satisfaction with family functioning of families caring for children with developmental disabilities. The research questions included:

1. What is the relationship among family and child characteristics, internal and external coping resources, and satisfaction with family functioning of families of children with developmental disabilities?
2. What do families perceive as being the difficult and helpful aspects of caring for a child with a developmental disability?

### **Method**

#### ***Sample***

A convenience sample of families who met the following criteria were approached to participate in the study: All spoke English, had one or more children with a developmental/cognitive and/or physical disability living at home, and used the services of a publicly funded respite care program at least once a year in a moderate size urban area. This program provided in-home or out-of-home respite care according to parents' requests. The duration of respite was also governed by family needs; some preferred short periods of respite (e.g. two half days per week), while others asked for weekend or vacation

relief. Families received an average of 20 to 24 days of relief annually. Fifty families (52.1% response rate) agreed to participate in the study by completing a demographic questionnaire, and measures of internal and external coping resources and satisfaction with family functioning. One member of each family completed the measures; 97% of respondents were mothers.

The majority of families (84%) had at least one other child living at home. The mean age of the developmentally disabled child was 11.7 years (range = 2 to 37 yrs.); 58% of these were female, and 90% were diagnosed with either developmental disabilities or neurological injuries and illnesses. The childrens' handicapping conditions and behaviour problems are listed in Table 1. Children were described as having an average of 3 to 4 handicapping conditions, and over half (n = 30) of these children had four or more conditions. In addition, more than half of the children were reported to have problematic behaviours.

**Table 1**  
**Characteristics of Children with Disabilities (N = 50)**

Conditions	n	%
Delayed Development	46	92
Hyperactivity	17	34
Physical Handicap	26	52
Severe Behavioural Problems	29	58
Severe Emotional Problems	16	32
Severe Hearing Problems	18	36
Severe Visual Problems	20	40
Seizures	13	26
Other	14	28
Behaviours		
Physical Harms Others	18	36
Harms Self	17	34
Destroys Property/Objects	14	28
Interferes with Sleep	26	52
Sexually Aggressive	1	2
Irritates Others in House	24	48

The majority of the parents were married (72%) and ranged in age from 28 to 64 years (fathers M = 42.0 yrs.; mothers M = 39.9 yrs.). The majority of fathers (86%) and less than half of the mothers (48%) were employed. Thirty-two percent of fathers and 28% of mothers had completed high school education, and 44% of fathers and 58% of mothers had completed college or university level education.



### **Procedure**

Families were informed of the general purpose of the study through a newsletter published by the respite program. Surveys were mailed to each family; consent was indicated by return of the completed questionnaire. A second mailing was conducted four weeks following the initial mailing, and two reminder notices were sent two weeks after each mailing.

### **Instruments**

*The Family Inventory of Resources for Management* (FIRM) measures a family's repertoire of resources that include family strengths, extended family social support, and financial well-being (McCubbin & Thompson, 1987). For the purpose of this study only the 35 questions related to family strengths (i.e., mastery and health, esteem and communication) were used to measure internal coping resources. The esteem and communication scale assesses support resources in the areas of family esteem, communication, mutual assistance, optimism, problem-solving, and encouragement of autonomy among family members (McCubbin & Thompson, 1987). The mastery and health subscale describes support resources along three dimensions: the sense of mastery over family events and outcomes, family mutuality, and physical and emotional health. McCubbin and Thompson (1987) reported internal reliability levels of .85 for both of these subscales as well as studies that support the validity of FIRM subscales. Test/re-test reliability was not reported.

*The Family Hardiness Index* (FHI) is a 20-item scale that measures hardiness as a family characteristic that buffers the family from the effects of stressors and demands thereby facilitating family adjustment and adaptation over time (McCubbin & Thompson, 1987). Satisfactory reliability ( $\alpha = .82$ ) and construct validity were reported by McCubbin and Thompson (1991). Test/re-test reliability was not reported.

*The Norbeck Social Support Questionnaire* (NSSQ) uses a nine-item scale to measure functional support, social network, and network loss. In addition, source scores can be obtained (i.e., the amount of functional support from spouse, friends, relatives, etc.). Evidence for construct validity was demonstrated through significant correlations between NSSQ and two similar interpersonal constructs. Test/re-test results indicated a high degree of stability over a seven-month period (Norbeck, Lindsey, & Carrieri, 1983). The NSSQ was selected for its ability to assess not only functional properties of social support, but also the network of social relationships on which families of handicapped children rely for support. It assesses three types of functional support: affect, affirmation, and aid. These categories were derived from Kahn (1979), who defined affect as social support that expresses liking, love, respect or admiration; affirming social support as expressions of agreement

with one's actions or statements; and aid as direct assistance. Kahn (1979) defines social support as transactions involving one or more of these properties.

The frequency of use of respite care was assessed to determine its unique impact on satisfaction with family functioning. Program records for the previous year were examined by the respite program director and families' use of respite care was scored as low frequency (less than 5 days per year), moderate frequency (6 to 25 days per year) or high frequency (26 or more days per year).

*The Feetham Family Functioning Survey* (FFFS) is a 25-item questionnaire that measures family satisfaction in three areas of functioning: (a) the relationships between the family and larger social units such as the community; (b) subsystems such as the division of labour; and (c) the relationships between the family and individual with particular attention paid to the parent-child relationship and the husband-wife relationship (Feetham & Humenick, 1981). For each statement, the respondent is asked three questions: (a) to what degree does a given function exist in your family, (b) how much do you believe that function should exist in your family, and (c) how important is that function is to you. A discrepancy score is obtained by calculating the difference between the degree to which a function exists, and how much the subject believes it should exist. High discrepancy scores reflect low levels of satisfaction with family functioning. Alpha coefficients for the total scores of how much the function exists was .66, for how much should it exist, .75 and for the discrepancy score was .81. Construct validity has been reported, and the test/re-test reliability was .85 (Feetham & Humenick, 1981). In addition, the instrument includes two open-ended questions designed to elicit families' perceptions of two issues: "What is most difficult for you now?", and "What is most helpful for you now?"

### *Data Analysis*

The completed questionnaire data were analyzed both quantitatively and qualitatively. First, individual instruments were scored according to the directions provided by the authors of the instruments and then descriptive statistics including range, means, and standard deviations were calculated. The second phase of the data analysis involved correlation analysis and regression in order to examine the relationships between the demographic data, the measures of coping, social support, and family functioning.

Finally, the qualitative data from the FFFS were subjected to content analysis. Answers to the open-ended questions were reviewed for commonly occurring themes and patterns. Using an inductive approach to category development, similar statements were labelled and grouped into mutually exclusive topical categories, and then further grouped into conceptual cate-

gories (Corbin, 1986). Each statement that described a parent's experience was coded only once and placed into one of the major categories. Fifteen per cent of the surveys ( $n=8$ ) were randomly chosen to determine inter-rater reliability for coding, using Cohen's kappa, which is particularly sensitive to nominal data (Hollenbeck, 1978). The inter-rater reliability for the present study was .90.

## Results

The means and standard deviations for all measures are presented in Table 2. The internal coping resources assessed were hardiness, mastery and health, and esteem and communication. The scores for each of these internal resources are in the normal range, although the hardiness scores and the mastery/health scores are at the lower end of the normal range (McCubbin & Thompson, 1991).

The external resource of social support was measured by the NSSQ. The total functional score for these families was lower than normative data ( $M = 119.8$  vs. 201.90), as was the total network score ( $M = 48.65$  vs. 107.68). The total loss score was slightly higher, ( $M = 3.02$  vs. 2.86) (Norbeck, Lindsey & Carrieri, 1983). In the current study scores were calculated by separately summing the item ratings for the six functional support items. However, since the method for calculation of support from individual sources is not clear in previous studies no normative data are available for comparison with

**Table 2**

**Range, Means, and Standard Deviations of Measures  
in Families of Children with Disabilities (N = 50)**

Measure	Mean	SD	Range
Child Conditions	3.78	1.66	1-7
Child Behaviour Problems	2.74	1.70	0-6
Family Hardiness Index	41.10	8.68	12-58
FIRM			
Esteem and Communication	34.67	5.85	19-45
Mastery and Health	30.27	12.26	5-51
NSSQ			
Functional Support	119.80	44.79	24-232
Social Network	48.65	16.12	9-81
Network Loss	3.02	3.67	0-16
Source of Support			
Spouse	26.33	4.23	16-30
Family	21.94	6.32	5-30
Friends	21.26	6.09	7-30
Work Colleagues	15.44	5.55	6-28
Others	11.54	4.02	6-16
Feetham Family Functioning			
Discrepancy Score	33.17	14.96	10-76

Note: Theoretical ranges: Family Hardiness Index 0-80; FIRM [Subscales: Esteem and Communication 0-45, Mastery and Health 0-60]; NSSQ-Functional Support 0-270; Feetham Family Functioning 0-150.

Table 3

Zero-Order Correlations Between Measured Variables in Families with Disabilities (N=50)

Variables	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
<b>Child-Parent Characteristics</b>																	
1. Child's Age	1.00																
2. Child's Behaviour	.23	1.00															
3. Child's Condition	.20	.28	1.00														
4. Mother's Age	.71***	.18	-.18	1.00													
5. Father's Age	.68***	.11	-.15	.94***	1.00												
<b>Resources - (Internal)</b>																	
6. Esteem	.04	.15	-.42**	.05	.09	1.00											
7. Mastery	.10	.05	-.37**	.25	.16	.46**	1.00										
8. Hardiness	.03	-.10	-.36**	.08	.06	.03***	.59**	1.00									
<b>Resources - (External)</b>																	
9. Total Function	.14	.20	.11	.12	.15	.29*	.16	.40*	1.00								
10. Total Network	-.03	.19	.28	-.01	-.04	.16	.01	.28	.89***	1.00							
11. Total Loss	-.23	-.14	.17	-.20	-.21	.06	-.17	-.01	.13	.17	1.00						
12. Frequency of Respite	.19	-.05	-.05	.20	.25	-.08	-.04	-.08	.19	.21	-.27	1.00					
<b>Resources - (Sources)</b>																	
13. Spouse	.15	-.03	-.08	.03	.02	.51**	.46**	.53**	.40*	.30	.03	-.03	1.00				
14. Family	-.04	-.10	.14	.05	.17	.20	.07	.36*	.56***	.47**	-.04	.31*	.39**	1.00			
15. Friends	-.17	-.09	-.06	-.11	-.05	.26	.18	.31*	.51***	.38*	-.15	.06	.38*	.42**	1.00		
16. Co-workers	-.12	.26	.09	.03	.12	.56**	.22	.56**	.72***	.50*	.06	-.19	.43*	.50**	.61**	1.00	
<b>Dependent Variables</b>																	
17. Family Functioning Discrepancy Score	-.24	.05	.21	-.17	-.18	-.26	-.56***	-.39*	-.30	-.09	.11	-.009	-.61***	-.14	-.35*	-.12	1.00

\*p<.05; \*\*p<.01; \*\*\*p<.001



these scores. The frequency of use of respite care was reported as low for 29% of the sample, moderate for 40%, and high for 31%.

Satisfaction with family functioning scores were similar to those from other similar populations ( $M = 33.2$  vs.  $29.83$ ) (Failla & Jones, 1991). Respondents reported high discrepant scores (i.e., low levels of satisfaction) and high importance scores for items that described family functions involving children (i.e., number of problems with children, and number of times children missed school).

Correlations between child and parent characteristics, internal and external coping resources including frequency of respite use, and satisfaction with family functioning are summarized in Table 3. None of the child or parent characteristics, coping resources, or satisfaction with family functioning correlated significantly with families' frequency of use of respite services. Hierarchical regression analyses were performed on satisfaction with family functioning scores, using child characteristics, and internal and external coping resources (excluding frequency of use of respite service) as predictors (Table 4). The variables were entered in three blocks: first, the handicapped child's age, and number of conditions and behaviours were entered as indicators of stress; next, internal coping resources (namely esteem and communication, mastery and health, and hardiness) were entered; lastly, the external resources of social support from each of four categories of persons in the social network (the

**Table 4**

**Hierarchical Regression of Satisfaction with Family Functioning  
in Families of Children with Disabilities**

Variables	Beta <sup>a</sup>	F	R <sup>2</sup> change
<b>Child Characteristics</b>			
Child Age	-.12	.94	.05
Conditions	.02	.01	
Behaviours	-.04	.09	.02
<b>Coping Internal</b>			
Hardiness	-.10	.32	
Mastery/Health	-.33	5.13*	
Esteem/Communication	.14	.61	.25**
<b>Coping External</b>			
<b>Sources of Social Support</b>			
Spouse	-.48	12.62**	
Family	.07	.32	
Friends	-.35	6.10*	
Co-worker	.18	1.59	
other	.22	2.83	.24**

R<sup>2</sup> = .57

\* $p < .05$ ; \*\* $p < .01$

<sup>a</sup>Beta coefficients are from the regression equation with all the variables entered.

spouse, family, friends, and co-workers) were entered. These were the primary sources of support identified by these families. The ratings of support from individual sources of support were entered in the analysis because they correlated with satisfaction with family functioning discrepancy scores, whereas total scores for functional support, social network, and network loss did not.

This model accounted for 57% of the variance in satisfaction with family functioning. Child characteristics made no significant contribution to the model. However, both the internal and external coping resources added significantly to the variance accounted for in the family functioning discrepancy scores. More specifically, parents reporting higher levels of mastery and health reported greater satisfaction with family functioning (low discrepancy scores). In addition, the degree of support from spouse and friends were negatively related to discrepancy scores, indicating that higher levels of satisfaction with family functioning were significantly associated with higher levels of support from these sources.

In the open-ended FFFS items, families reported five common areas of difficulty. These included emotional and mental health concerns relative to parents' coping with day-to-day routines and stresses (i.e., "having too much to do"); isolation of either the child and/or family (i.e., "my child with special needs is never invited"; "she is so disruptive we usually stay at home to avoid embarrassing situations"); the child's behaviour and caregiving demands (i.e., "the needs increase and there does not seem to be a light at the end of the tunnel"); and vacations and family outings. When asked what is most helpful, the majority of these families reported that respite services in the home were the most helpful, followed by support from family and friends.

### **Discussion**

This study clearly illustrates the importance of internal and external coping resources in families caring for children with developmental disabilities. These families face significant stressors arising from the experience of caring for children with multiple and varied handicapping conditions. Surprisingly, the child's conditions and behaviours were not significantly related to satisfaction with family functioning. In spite of these challenges, families reported satisfactory internal coping resources such as hardiness, mastery and health, esteem and communication, and satisfaction with family functioning even when social support was limited. The question becomes, how do families grow and develop such strengths when stress is high and outside assistance is limited?

One possibility is that the experience of parenting a child with developmental handicaps is an opportunity for growth in these families. Previous

studies have found that parents do report positive experiences, including personal and family growth, in such circumstances (Summers, Behr & Turnbull, 1989). Perhaps internal coping resources such as family hardiness are strengthened by families' experiences. Although hardiness was not a significant predictor of satisfaction with family functioning in our model, it did correlate significantly with child conditions, other internal coping resources, and sources of social support, which suggests that it does play a role in the coping process. Future research might address the concept of growth as an outcome of the emotional experiences these families face, and examine how families learn to develop resilience in response to such extraordinary challenges.

The scores for total functional support were low relative to the normative scores reported by Norbeck, Lindsey and Carrieri (1983), but were consistent with those of Failla and Jones (1991) who studied a similar population. Why do families of children with developmental handicaps experience such low levels of functional and network social support throughout their children's early childhood and young adult years? Perhaps caregiving demands are so high that families have little time or energy to develop strong, long-term social networks. Future research is needed to better understand which family and/or social network characteristics contribute to families' abilities to develop and maintain strong, supportive social networks.

There was a significant correlation between all sources of support and the internal coping resource of hardiness. Specifically, families who reported high levels of support from spouse, family, and friends also reported higher levels of hardiness. Failla and Jones (1991) suggested that hardiness acts as a resistance resource that minimizes the effects of stress and increases the families' use of social support. Our regression analysis indicates that a significant portion of the variance in family functioning (discrepancy) scores was predicted by the variables of mastery and health and social support from spouse and friends. These findings are consistent with the work of Dunst, Trivette, and Cross (1986) who reported that satisfaction with support and the numbers of sources of support were significant predictors of parent and child well-being in families caring for children with disabilities. Hardiness may have an indirect effect on satisfaction with family functioning via its influence on social support. Future research could explore this issue.

In the current investigation child and parent characteristics, and coping resources did not correlate with the frequency of use of respite services. Nor was the frequency of use of respite service related to satisfaction with family functioning. These unexpected findings could have been due to the fact that only one source of respite care was measured. Respite can also be provided through relatives, friends, and child programs. Future research needs to consider all types of respite support available. Yet, it was clear that respite was an

important resource for these families; when asked what was most helpful to them, parents most frequently answered "respite service at home".

The results of the current study cannot be generalized to other populations because the sample was obtained by convenience. Although the sample was relatively small, using Cohen's (1992) table for power analysis, it approximates that necessary for sufficient statistical power with the number of predictors used in the current study.

### *Implications for Practice*

Interventions can be designed to extend and enhance individual and family coping. Nurses and other professionals can provide support through facilitation of personal networks, development of self-help groups, and community empowerment. In addition, Stewart (1993) suggests that nurses can play an important role in enabling families to develop and maintain resources of support. Summers, et al. (1989) suggest that professionals should encourage parents to maintain an optimistic and yet realistic view of their child, to recognize progress they and the child are making, and to be involved in decisions regarding their child's care. In addition, it is important that respite services be designed to meet the needs of families (Neef & Parrish, 1989). These efforts will foster the development of mastery and esteem in parents, which are important coping resources. Families caring for children with disabilities might benefit from such interventions.

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