

Family-Centered Caregiving and Well-Being of Parents of Children With Disabilities: Linking Process With Outcome

Gillian King,¹ PhD, Susanne King,² MSc, Peter Rosenbaum,² MD, FRCP(C), and Richard Goffin,³ PhD

¹Thames Valley Children's Centre, ²CanChild, McMaster University, and ³University of Western Ontario

Objective: This study examined the strength of the relationship between parents' perceptions of family-centered, professionally provided caregiving and their emotional well-being (feelings of distress and depression). This was done in the context of other factors that might affect well-being (child behavior problems, coping strategies of parents, protective factors in the social environment, child factors related to disability, and family factors).

Method: We asked 164 parents of children with nonprogressive neurodevelopmental disorders (primarily cerebral palsy, spina bifida, or hydrocephalus) to complete a series of instruments measuring the constructs of interest.

Results: Structural equation modeling showed that more family-centered caregiving was a significant predictor of parents' well-being. The most important predictors of well-being were child behavior problems and protective factors in the social environment.

Conclusions: Services are most beneficial when they are delivered in a family-centered manner and address parent-identified issues such as the availability of social support, family functioning, and child behavior problems.

Key words: professional caregiving; parent emotional well-being; children with physical disabilities; family-centered service.

Parents of children with disabilities are more likely to experience depression and distress than are other parents, but there is considerable variability in their emotional well-being (Cadman, Rosenbaum, Boyle, & Offord, 1991; Kronenberger & Thompson, 1992). The role of family-centered caregiving *by service providers* (hereafter referred to as "caregiving")

has not been examined systematically as one of the many factors that may affect parents' emotional well-being (Rosenbaum, King, Law, King, & Evans, 1998). Family-centered care involves ensuring that parents have ultimate control over decision making, treating parents respectfully and supportively, and providing parents with needed information (King, King, & Rosenbaum, 1996). Studies have looked at factors affecting the emotional well-being of parents of children with disabilities but have not

All correspondence should be sent to Gillian King, Thames Valley Children's Centre, 779 Base Line Road East, London, Ontario, Canada N6C 5Y6. E-mail: gillking@fhs.csu.mcmaster.ca.

looked at the role of family-centered care in predicting well-being and have not examined a comprehensive set of variables (e.g., Kronenberger & Thompson, 1992; Quittner, Glueckauf, & Jackson, 1990; Wallander et al., 1989c). The purpose of the present study was to determine whether (and to what extent) family-centered caregiving helps to lessen the feelings of distress and depression that some parents experience in raising a child with a disability. Determining the relative importance of factors in predicting parents' well-being will help service providers direct their efforts to benefit parents.

Initial Conceptual Model

Our model of the factors affecting the well-being of parents of children with disabilities was based on a risk and resilience model proposed by Wallander to account for the differential adaptation of mothers of children with physical disabilities (Wallander et al., 1989c). Wallander's model contains risk factors (parameters of the child's disability, functional care strain, and psychosocial stress) and resistance factors that ameliorate mothers' negative response to the stress of having a child with a disability (social-ecological factors such as social support, intrapersonal strengths, and coping). Our process-outcome model (see Figure 1) categorizes factors in a process-outcome framework, while retaining Wallander's risk and resilience conceptualization. The model contains (a) prognostic indicators (demographic factors and disability parameters, which are both risk factors); (b) professional caregiving process (a protective factor); (c) mediating variables, which are a combination of risk and protective factors (social-ecological factors, psychosocial life stressors, and parents' coping strategies); and (d) parental outcomes (satisfaction with care and parent emotional well-being).

Specific Causal Pathways/Hypotheses Tested

Here we define the eight constructs in our model and briefly cite evidence for their links to the other constructs (as indicated by the arrows in Figure 1).

1. Demographic factors (parents' education, employment, and family income). We hypothesized that better demographic factors (higher education, etc.) would be related to (a) fewer psychosocial life stressors (after Wallander, Varni, Babani, Banis, &

Wilcox, 1989b), and (b) better parent emotional well-being (after Sloper & Turner, 1993).

2. Disability parameters (child's functional dependence and severity of disability). We hypothesized that lower levels of disability would be related to (a) fewer psychosocial life stressors (after Wallander et al., 1989a), and (b) parents' perceptions of caregiving as more family-centered (after King, Rosenbaum, & King, 1995).

3. Caregiving process. We expected that more family-centered caregiving would be related to (a) social-ecological factors (i.e., better family functioning and higher satisfaction with social support), (b) decreased life stress (psychosocial life stressors), (c) higher satisfaction with services (after King, King, and Rosenbaum, 1996), and (d) better emotional well-being.

4. Social-ecological factors. We postulated that the presence of these factors (specifically, better family functioning and greater social support) would be associated with (a) fewer psychosocial life stressors (after Tausig, 1992; Wallander et al., 1989b), and (b) better parent emotional well-being (after Kronenberger & Thompson, 1992).

5. Psychosocial life stressors (child behavior problems and day-to-day burden). We hypothesized that fewer life stressors would predict better well-being (after Quittner et al., 1990).

6. Coping strategies. We hypothesized that the use of fewer coping strategies would be associated with (a) the presence of social-ecological factors (after Margalit, Raviv, & Ankonina, 1992), and (b) better parent emotional well-being (after Barakat & Linney, 1995).

7. Satisfaction with care. We hypothesized that higher satisfaction would be related to better parent emotional well-being.

8. Parent emotional well-being. Decreased well-being consists of symptoms of depression (sadness, inactivity, difficulty in thinking or concentrating, feeling dejected or hopeless), distress (being worried or troubled), or the state of stress (physical or mental tension).

Structural Equation Modeling

We used structural equation modeling (SEM) to examine (a) the relationship between parents' perceptions of caregiving and their emotional well-being, and (b) the roles played by a wide range of other factors in mediating this relationship or directly predicting well-being. Structural equation modeling

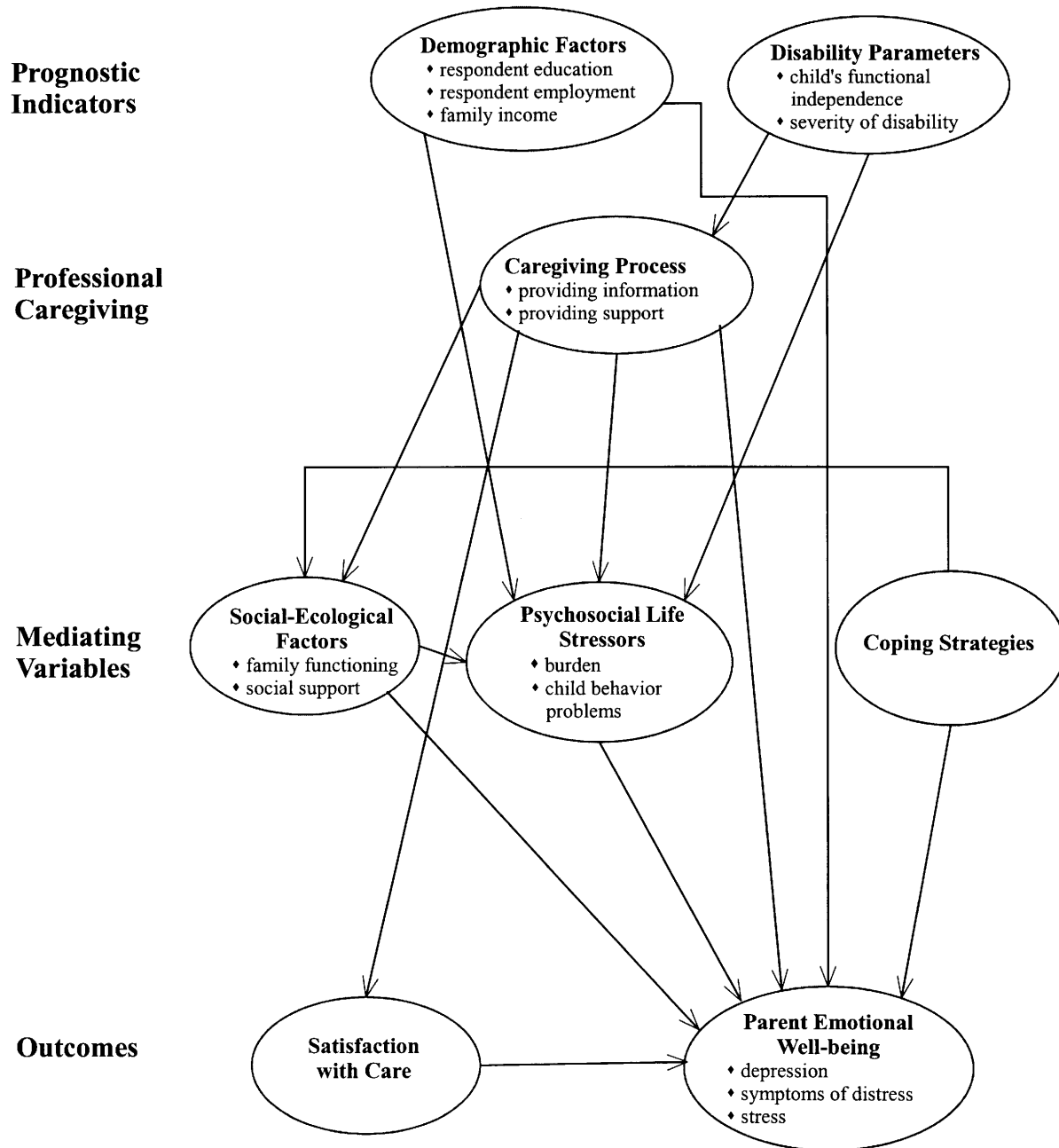


Figure 1. Conceptual model of factors influencing psychosocial outcomes for parents of children with disabilities.

is a popular analytical technique in the social sciences (Goffin & McLennan, 1997) and ideally suited to the aims of this study. It provides a measure of overall model fit and incorporates error in measurement into the model (Peyrot, 1996). It allows the simultaneous consideration of multiple pathways between constructs and therefore allows researchers

to test a relatively complex theory in a single analysis (Goffin & McLennan, 1997). The path coefficients that emerge often reveal a system of relations between latent constructs that would be far from obvious on the basis of a visual inspection of zero-order relations. Latent variables are typically operationalized by employing two or more directly mea-

sured variables in such a way that only variance common to all the indicators is used to represent a construct (i.e., extraneous variance is "partialled" out of the model).

Method

Participants

Participants were mothers and fathers of children on the caseloads of six publicly funded children's rehabilitation centers in Ontario, Canada. The 20 children's rehabilitation centers in Ontario comprise the Ontario Association of Children's Rehabilitation Services, which has endorsed and adopted a family-centered service philosophy involving partnership between parents and professionals, supportive and respectful treatment, and information exchange (Rosenbaum et al., 1998). Families were enrolled in the study if they (a) had a child between 3 years and 5 years, 11 months with a nonprogressive neurodevelopmental disorder (cerebral palsy, spina bifida, or hydrocephalus), (b) had received services from the center for at least six months, and (c) were able to speak, read, and write English. Data were obtained from 175 parents (a return rate of 85%, based on the number of initially consenting parents who actually did participate). Due to missing data, the final sample consisted of 164 parents (103 mothers and 61 fathers of 109 children with disabilities).

Instruments

Demographic Factors. Education was measured using an 8-item checklist, employment status was a dichotomous variable, and family income was measured using a 7-item checklist.

Disability Parameters. There were three indicators of disability parameters: (1) functional independence of child (measured by the WeeFIM; Msall, Mallen, Rogers, Catanzaro, & Duffy, 1991); (2) number of services currently received by the child (an indicator of severity of disability), measured by a checklist; and (3) number of current health or development problems of the child (an indicator of severity), measured by a checklist. The WeeFIM is a widely used measure of the functional status of children ages 6 months to 8 years that measures burden of care. The WeeFIM has been used exten-

sively with children with physical disabilities and has excellent test-retest reliability and good concurrent validity (Msall et al., 1996). All three indicators were keyed so that higher scores on this construct indicated less complex child needs.

Caregiving Process. Caregiving process was measured using five indicators corresponding to the Measure of Processes of Care (MPOC) scales (King, Rosenbaum, & King, 1996): Enabling and Partnership, Providing General Information, Providing Specific Information About the Child, Coordinated and Comprehensive Care for the Child and Family, and Respectful and Supportive Care. The MPOC is a 56-item questionnaire measuring parents' perceptions of the extent to which important behaviors of health care professionals occur (i.e., the extent to which rehabilitation services are delivered in a family-centered manner; see King, Rosenbaum, & King 1996). Test-retest reliabilities range from .78 to .88 for the five scales, and the internal consistency reliabilities range from .81 to .96. Higher scale scores indicate better care in the eyes of parents.

Social-Ecological Factors. There were two indicators: (1) the General Functioning scale of the Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 1983) and (2) the Satisfaction with Social Support score from the Social Support Questionnaire-6 (SSQ6; Sarason, Sarason, Shearin, & Pierce, 1987). The FAD is a 53-item scale measuring seven dimensions of family functioning. The General Functioning Subscale has satisfactory internal consistency (Cronbach's alpha = .86) and good concurrent validity (Byles, Byrne, Boyle, & Offord, 1988). The Satisfaction with Social Support score from the SSQ6 measures the adequacy of social support. The SSQ6 has excellent test-retest reliability ($r = .85$), internal consistency (Cronbach's alpha = .96), and concurrent validity (Sarason et al., 1987). Higher scores on this construct indicated less adequate social-ecological support.

Psychosocial Life Stressors. There were eight indicators: (1) the Mastery, Financial Impact, Personal Strain, and Familial/Social scale scores from the Impact on Family Scale (IOF; Stein & Riessman, 1980), and (2) the Conduct Disorder, Hyperactivity Disorder, Emotional Disorder, and Somatization scale scores from the Survey Diagnostic Instrument (SDI; Boyle et al., 1987). The IOF is a 24-item scale that yields a total score and four subscores measuring impact on various components of family life. It has adequate internal consistency (Stein & Riessman,

1980). The SDI provides measures of four behavioral and emotional problems (listed above) and has adequate test-retest reliability (87% agreement) and adequate internal consistency (Boyle et al., 1987). Higher scores on this construct indicated the presence of more life stressors.

Coping Strategies. The three subscales of the Coping Health Inventory for Parents (CHIP; McCubbin, 1991) were used: (1) Family Integration, Cooperation, and an Optimistic Definition of the Situation; (2) Maintaining Social Support, Self-Esteem, and Psychological Stability; and (3) Understanding the Health Care Situation Through Communication With Other Parents and Consultation With the Health Care Team. The CHIP scales have adequate internal consistency (Cronbach's alpha = .71 to .79) and satisfactory concurrent validity (McCubbin, 1991). Higher scores on this construct indicated better coping (i.e., the use of fewer coping behaviors).

Satisfaction With Care. The Client Satisfaction Questionnaire (CSQ; Larsen, Attkisson, Hargraves, & Nguyen, 1979) is an 8-item standardized measure of satisfaction with high internal consistency (Cronbach's alpha = .93) and adequate concurrent validity. Higher scores indicated greater satisfaction with care.

Parent Emotional Well-being. There were three indicators. The first was the Global Severity Index from the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1992), which has good test-retest reliability (estimates range from .78 to .90), good internal consistency (Cronbach's alpha = .77 to .90 for the subscales), and satisfactory concurrent validity (Derogatis, 1992; Tennen, Affleck, & Herzberger, 1984). The second indicator was the total score from the Centre for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977), which is a 20-item "state" measure of depression assessing the frequency and duration of cognitive, affective, and behavioral symptoms during the past 1-week interval. According to Radloff (1977), the measure has adequate test-retest reliability (estimates range from .51 to .67) and satisfactory internal consistency (Cronbach's alpha = .84 to .90). The third indicator was a one-item measure of stress. Parents were asked to indicate, using a 5-point scale, "the degree to which caregiving by the center has affected the amount of stress and worry you experience in caring for your child (in the past year or less)." The test-retest reliability of this question is acceptable (a weighted

kappa of .67; King et al., 1995). Lower scores on this construct indicated better well-being.

Procedure

Parents were invited to participate by their child's rehabilitation center. Consenting parents were mailed the MPOC, which they returned by mail. The MPOC was given first to ensure that perceptions of caregiving did not affect the completion of the other measures. One month later parents were sent standardized questionnaires about their child, family, and emotional well-being, which they also returned by mail. Four to six weeks later, during a home interview, a research assistant obtained background information about the child and family, and administered the WeeFIM.

Approach to Structural Equation Modeling

We conducted SEM using the LISREL 8 statistical program (Joreskog & Sorbom, 1993). LISREL uses maximum likelihood estimation, which is the standard method of estimating free parameters and fit criteria (Hoyle & Panter, 1995). Reciprocal paths were not estimated in the model since predicting such two-way effects often leads to difficulties in determining models with adequate fit (Hayduk, 1987).

Results

Description of Families

Most respondents (85.3%) were from two-parent families, considered English to be their first language (95.6%), and lived in urban settings (85.3%). The majority (64.3%) had a family income between \$30,000 and \$75,000 and most mothers (58.7%) and fathers (57.8%) had beyond a high school education. Their children with disabilities ranged between 3 and 6 years and had an average of 3.3 health or development problems. The primary problem was a diagnosis of cerebral palsy (63.3%), followed by a diagnosis of spina bifida or hydrocephalus (16.6%). The majority (65.1%) of these children received between five and seven kinds of rehabilitation services. Most (68.8%) received services on at least a monthly basis, and most (89.9%) had been visiting their rehabilitation center for at least two years.

Preliminary Analyses

We performed hierarchical regression analyses on key outcome measures to determine whether mothers and fathers from the same couple could be treated as independent cases. Family variables and MPOC scores were included as predictors and entered as one block. Intraclass correlation coefficients on the residuals from these analyses were low (.10 to .17), indicating that mothers and fathers responded independently to the questionnaires. No threats to the veracity of the findings on the basis of distributional assumptions were evident.

Structural Equation Modeling

The Measurement Model. Table I presents the mean scores, standard deviations, and zero-order correlations between the directly measured variables. The development of a measurement model is often recommended as a first step in conducting SEM (Anderson & Gerbing, 1988). A measurement model specifies how the directly measured variables are related to the latent variables. Accordingly, using confirmatory factor analysis, we examined the indicators for each construct statistically to determine whether they did in fact load significantly on the expected latent variables (Joreskog, 1993). Three indicators of satisfaction with care (substantively grouped subsets of the CSQ items) were created to provide multiple indicators for the measurement of the satisfaction construct.

Testing the fit of the measurement model led to three refinements to the conceptual model presented in Figure 1. First, the stress variable was found to have low empirical relationships with the other variables measuring parental well-being. Consequently, stress was treated as a separate variable in the analysis of the structural model. Second, confirmatory factor analysis indicated that caregiving was better represented by two rather than five indicators from the MPOC measure (Providing General Information and Providing Support; these two indicators together contained all 56 MPOC items). Third, the psychosocial life stressors construct was divided into two constructs: burden and child behavior problems.

The final measurement model was acceptable, suggesting that the indicators of the latent variables did operationalize each construct adequately. The estimates of model fit were $\chi^2(280) = 559.53$, $p < .01$; root mean square error of approximation

(RMSEA; see Steiger, 1990) = .08; Tucker-Lewis Index (TLI; see Tucker & Lewis, 1973) = .84; relative noncentrality index (RNI; see Goffin, 1993) = .87. The loadings of the directly measured variables on the latent variables are presented in Table II, along with standard errors for the freed parameters in the model and error variances for all parameters. All loadings were substantial in magnitude, significantly different from zero, and had valences consistent with expectations, indicating that the latent variables were adequately operationalized by the directly measured variables.

The Structural Model. A structural model was then specified, in which we indicated (a) exogenous variables (those not caused by any other latent variable; namely disability parameters, demographic factors, and coping strategies), (b) endogenous variables (those caused by other variables; namely, social-ecological factors, burden, child behavior problems, caregiving process, stress in dealing with the center, satisfaction with care, and parent emotional well-being), and (c) the pathways between the latent variables. Following standard SEM methodology, the pathways in the initial structural model were proposed on the basis of existing theories and logical inferences. Since the measurement model led to refinements in the constructs, the predicted pathways were not identical to those proposed in Figure 1. Further, we revisited the question of directionality and refined our model so that child behavior problems predicted social-ecological factors (rather than the reverse). All theoretically justifiable paths were initially included and remained in the model to the extent that they were supported by the analyses (Silvia & MacCallum, 1988).

Our final model (see Figure 2) had adequate goodness of fit, $\chi^2(309) = 634.09$, $p < .01$; RMSEA = .08; TLI = .83; RNI = .85. One parameter (error variance of the Providing Support indicator) was constrained at zero in order to obtain a proper solution in accordance with conventional SEM recommendations (van Driel, 1978). The ellipses in Figure 2 indicate the latent constructs, and the numbers above the solid lines represent standardized path coefficients reflecting the strengths of the presumed causal effects. For example, the .66 coefficient between caregiving and satisfaction with care indicates a .66 standard deviation increase in satisfaction for every increase of one standard deviation in the perception of caregiving. All pathways in Figure 2 were statistically significant. Following standard SEM conventions, the short, dashed arrows

Table 1. Means, Standard Deviations, and Correlations Among Directly Measured Variables

	PI	PS	GF	SS	M	FI	St	FS	C	HD	ED	So	SC1	SC2	SC3	D	GS	Str	Fln	Se	P	Ed	Em	I	Fit	MS	U	
PI	1.00																											
PS	.60	1.00																										
GF	-.03	-.12	1.00																									
SS	.18	.23	-.38	1.00																								
M	-.07	-.10	.58	-.27	1.00																							
FI	-.01	-.17	.25	-.25	.11	1.00																						
St	-.07	-.23	.34	-.36	.25	.76	1.00																					
FS	-.02	-.15	.29	-.27	.29	.68	.87	1.00																				
C	.09	.07	.31	.06	.21	.06	.11	.08	1.00																			
HD	.14	.16	.20	.01	.06	.09	.15	.14	.53	1.00																		
ED	.22	.06	.29	-.02	.18	.23	.31	.31	.46	.51	1.00																	
So	.11	-.05	.28	-.03	.07	.30	.30	.28	.24	.21	.52	1.00																
SC1	.30	.56	.03	.03	-.09	-.22	-.26	-.14	-.03	.00	.01	-.01	1.00															
SC2	.37	.64	.00	.03	-.06	-.20	-.24	-.13	.01	.12	.02	-.08	.79	1.00														
SC3	.35	.59	-.01	.09	-.08	-.14	-.22	-.06	-.07	.03	-.01	-.05	.77	.88	1.00													
D	-.09	-.12	.44	-.27	.21	.24	.27	.26	.31	.32	.40	.33	-.04	-.04	-.01	1.00												
GS	-.03	-.11	.38	-.17	.17	.16	.27	.26	.37	.43	.50	.38	-.05	-.07	-.07	.77	1.00											
Str	-.26	-.54	-.07	-.23	.04	.07	.18	.06	.04	.03	.01	.15	-.58	-.60	-.65	.12	.17	1.00										
Fln	.03	.22	-.12	.10	-.19	-.42	-.55	-.53	.15	.00	-.13	-.12	.27	.24	.18	-.05	-.07	-.12	1.00									
Se	.07	-.13	.10	-.09	.00	.25	.24	.23	-.02	.06	.07	.08	.02	-.01	.00	.06	.12	.02	-.46	1.00								
P	-.05	-.05	-.01	-.07	.02	.34	.40	.42	-.08	.20	.13	.12	-.14	-.13	-.12	-.04	-.02	.04	-.55	.26	1.00							
Ed	-.16	-.19	-.04	.02	-.09	-.11	-.17	-.16	-.08	-.12	-.10	-.02	.03	-.07	-.08	-.14	-.15	.11	.20	-.13	-.07	1.00						
Em	-.08	-.06	-.12	-.12	-.03	-.15	-.17	-.11	-.18	-.17	-.22	-.17	.08	-.02	-.02	-.25	-.22	.11	.11	.09	-.07	.31	1.00					
I	-.19	-.07	-.19	.05	-.15	-.17	-.09	-.02	-.21	-.16	-.30	-.16	-.10	-.10	-.10	-.16	-.18	.15	-.03	.07	.16	.23	.30	1.00				
Fit	.20	.37	-.44	.39	-.41	-.15	-.27	-.20	-.05	-.02	-.13	-.08	.26	.27	.30	-.18	-.10	-.23	.31	-.12	-.10	-.10	-.10	.00	1.00			
MS	.16	.19	-.21	-.20	-.19	-.19	-.28	-.17	-.02	-.09	-.03	.03	.14	.12	.15	-.10	-.10	-.08	.21	-.13	-.13	-.01	.04	.03	.62	1.00		
U	.21	.38	-.15	.17	-.14	.02	.00	.04	.16	.10	.07	.05	.16	.18	.21	.02	.04	-.19	.01	.09	.19	-.30	-.23	-.10	.46	.40	1.00	
M	4.3	21.5	1.8	5.1	7.3	6.4	21.7	18.7	1.1	3.2	3.2	2.8	7.0	6.5	12.8	12.9	.64	2.3	67.6	6.1	3.3	4.6	.7	4.1	37.4	28.0	13.6	
SD	1.52	4.33	.48	.85	1.77	2.29	5.64	5.06	1.99	2.72	2.81	3.00	1.29	1.48	2.47	10.06	.55	1.05	5.17	1.62	1.58	.48	1.72	1.55	9.42	9.29	5.24	

PI = Providing General Information; PS = Providing Support; GF = General Functioning Scale; SS = Satisfaction With Social Support; M = Mastery; FI = Financial Impact; St = Personal Strain; FS = Familial/Social; C = Conduct Disorder; HD = Hyperactivity Disorder; ED = Emotional Disorder; So = Somatization; SC1 = Satisfaction With Care Set 1; SC2 = Satisfaction With Care Set 2; SC3 = Satisfaction With Care Set 3; D = Depression; GS = Global Severity Index; Str = Stress; Fln = Functional Independence; Se = Number of Services; P = Number of Problems; Ed = Respondent Education; Em = Respondent Employment; I = Family Income; Fit = Family Integration; MS = Maintaining Social Support; U = Understanding the Health Care Situation.

Table II. Measurement Model: Loadings of Directly Measured Variables on Latent Variables (Standard Errors for Freed Parameters and Error Variances)

Directly measured variables	Latent Variables									
	Disability parameters	Demographic factors	Coping	Caregiving process	Soc.-ecol. factors	Burden	Child beh. problems	Satis. with care	Parent emo. well-being	Stress
Funct. Ind. (WeeFIM)	.96 (.075, .09)									
No. of services	-.47 (.078, .78)									
No. of problems	-.58 (.078, .67)									
Resp. education	.47 (.098, .78)									
Resp. employ.	.63 (.103, .60)									
Fam. income	.49 (.099, .76)									
Fam. integration (CHIP)		.98 (.076, .03)								
Main. soc. supp. (CHIP)		.63 (.077, .60)								
Understanding health care situation (CHIP)		.48 (.079, .77)								
Prov. general info (MPOC)			.60 (—, .65)							
Prov. support (MPOC)			1.00 (.151, .00)							
Gen. funct. scale (FAD)				.79 (—, .37)						
Satis. with social support (SSQ6)					-.50 (.010, .75)					
Mastery (IOF)						.27 (—, .93)				
Fin. impact (IOF)						.77 (.227, .40)				
Pers. strain (IOF)						.98 (.282, .05)				
Fam./social (IOF)						.89 (.257, .21)	.61 (—, .62)			
Conduct disorder (SDI)							.65 (.102, .58)			
Hyperactivity disorder (SDI)							.78 (.110, .38)			
Emotional disorder (SDI)							.53 (.096, .72)			
Somatization (SDI)								.83 (—, .30)		
Satis. with care set 1 (CSQ)								.95 (.058, .10)		
Satis. with care set 2 (CSQ)								.93 (.058, .13)		
Satis. with care set 3 (CSQ)									.84 (—, .30)	
Depression (CES-D)									.92 (.85, .16)	
Global severity index (SCL-90-R)										.84 (—, .30)
Stress										

This table contains the lambda-y and lambda-x loading matrices from the completely standardized solution. Standard errors can be estimated only for freed parameters in the model (for each endogenous latent variable, only one directly measured variable was fixed, as indicated by a dash in the table). The loading of the stress indicator on the stress latent variable was fixed at .84 based on a previous reliability estimate (a loading cannot be estimated when there is a single indicator).
 WeeFIM = Functional Independence Measure of Children (Msall, Mallen, Rogers, Catanzaro, & Duffy, 1991); CHIP = Coping Health Inventory for Parents (McCubbin, 1991); MPOC = Measure of Processes of Care (King, Rosenbaum, & King, 1996); FAD = Family Assessment Device (Epstein, Baldwin, & Bishop, 1983); SSQ6 = Social Support Questionnaire-6 (Sarason, Sarason, Shearin, & Pierce, 1987); IOF = Impact on Family Scale (Stein & Riessman, 1980); SDI = Survey Diagnostic Instrument (Boyle et al., 1987); CSQ = Client Satisfaction Questionnaire (Larsen, Attkisson, Hargraves, & Nguyen, 1979); CES-D = Centre for Epidemiological Studies-Depression (Radloff, 1977); SCL-90-R = Symptom Checklist-90-R (Derogatis, 1992).

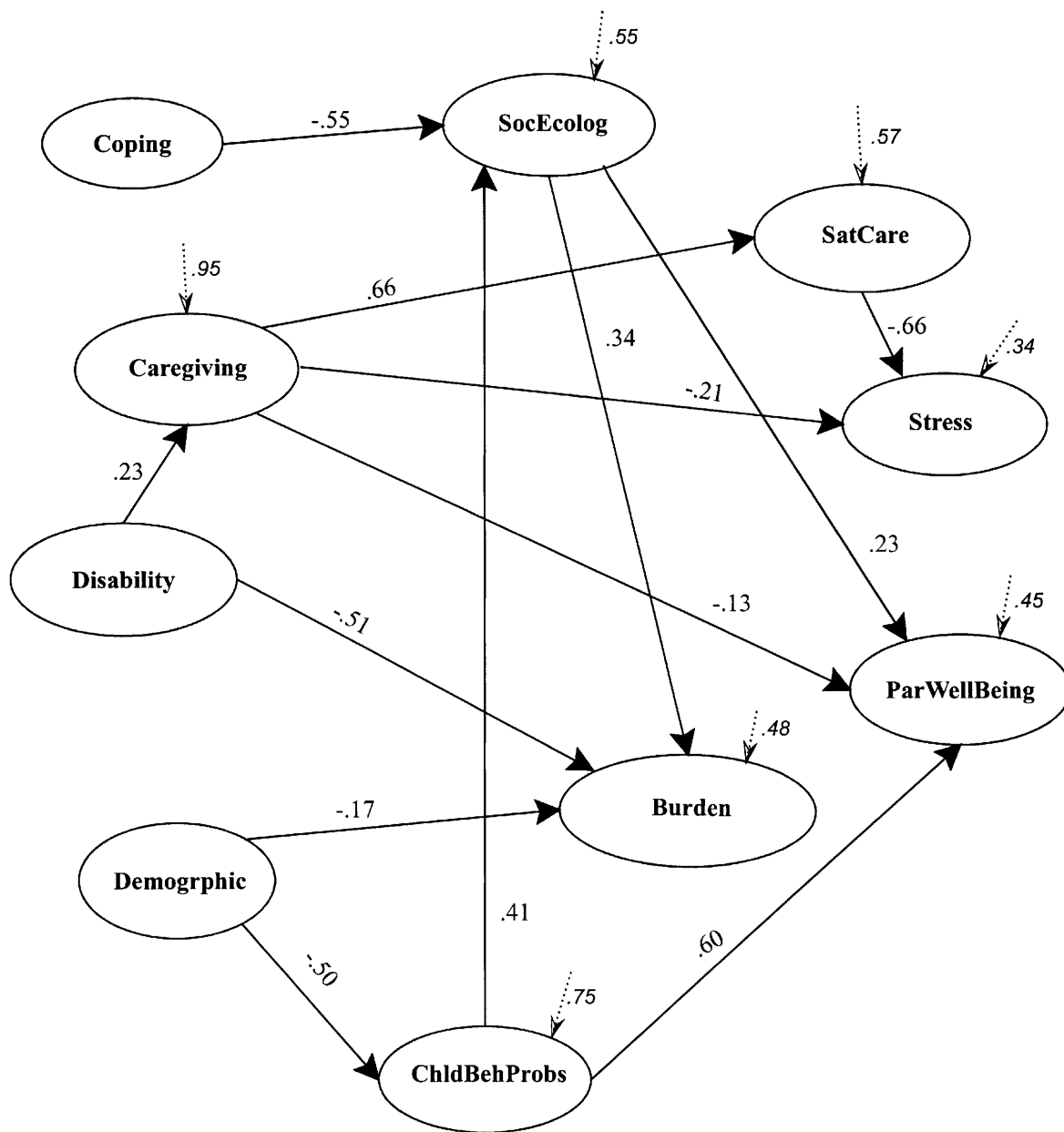


Figure 2. Path diagram of factors influencing psychosocial outcomes for parents of children with disabilities. Parameter estimates (path coefficients) are based on a solution in which all latent and directly measured variables were stabilized. The exogenous variables in the model are Coping, Disability, and Demographic. The short, dashed arrows symbolize “disturbance terms” (error variances of the endogenous variables). They refer to the amount of variance in the endogenous latent variables that is not explained by the structural equation model.

Coping = coping strategies of parents; Disability = child factors related to disability; Demographic = characteristics of family; Caregiving = parental perceptions of caregiving; SocEcolog = protective factors in the social environment; Burden = parents’ perceptions of the impact of the child’s disability; ChldBehProbs = child behavior problems; SatCare = parents’ satisfaction with care provided by the rehabilitation center; Stress = parents’ perception of stress experienced in dealing with the rehabilitation center; ParWellBeing = parents’ feelings of depression and distress.

symbolize “disturbance terms” (i.e., the amount of variance in the endogenous variables not explained by the model).

Statistically Significant Pathways

In this section, we relate the findings to the predictions made when we specified our structural model, using the refined constructs indicated by the measurement model.

Demographic Factors. We predicted relationships with child behavior problems, burden, parent stress, and parent emotional well-being. The presence of better demographic factors (higher education, etc.) was associated with both fewer behavior problems and decreased burden.

Disability Parameters. We predicted relationships with child behavior problems, burden, and parents’ perceptions of caregiving. Lower levels of disability were associated with both less burden and perceptions of caregiving as more family-centered.

Caregiving Process. We predicted that caregiving would affect social-ecological factors (i.e., family functioning and satisfaction with social support), child behavior problems, burden, parent satisfaction with services, parent stress, and parent well-being. We found significant pathways between more family-centered caregiving and the three parental outcomes: more satisfaction with services, less stress, and better emotional well-being.

Social-Ecological Factors. We predicted that the presence of protective social-ecological factors would be associated with decreased burden, less parent stress, and better parent well-being. The presence of social-ecological factors was associated with lower parent burden and better parent well-being.

Child Behavior Problems. We hypothesized that these would be a significant predictor of social-ecological factors, parent stress, and well-being. We found child behavior problems to be a significant predictor of social-ecological factors and parent well-being.

Burden. We predicted, but did not find, relationships with stress and well-being.

Coping Strategies. We predicted that better (i.e., fewer) coping strategies would be associated with the presence of protective social-ecological factors, less parent stress, and better parent emotional well-being. We found coping predicted social-ecological factors.

Satisfaction With Care. We hypothesized that

higher satisfaction with care would be related to less parent stress and better parent well-being. The former was found.

Discussion

Significant Predictors of Outcomes for Parents

Building on Wallander et al.’s (1989c) conceptual model of factors affecting the adaptation of mothers of children with disabilities, we used SEM to test the fit of a model incorporating parents’ perceptions of the caregiving behaviors of service providers. The present study is the first to examine the relative importance of caregiving versus other factors in predicting parents’ emotional well-being. It should be noted that the study involved parent report data exclusively.

Although causal assumptions were made in the SEM procedures, the data were gathered using a cross-sectional study design. According to Hoyle and Panter (1995), a significant path coefficient is a necessary but not sufficient criterion to infer a causal relation. Rather, causality is established using logic, manipulation of variables, or strong theoretical argument. In the following discussion we use the term “predictor” to indicate the direction of the pathways examined, but this should not be interpreted as conclusive evidence of cause and effect.

There were three main findings in the structural model. First, family-centered caregiving was a significant predictor of parents’ emotional well-being, their satisfaction with services, and (negatively) the stress they experienced in dealing with their child’s rehabilitation center. Thus, there are important links between caregiving process and parents’ outcomes. This is the first study to show a relationship (albeit small in magnitude) between family-centered caregiving and parents’ feelings of distress and depression. Although we cannot conclude that a cause-and-effect relationship exists, the data are consistent with the view that delivering services in a family-centered way is associated with better parental well-being. The findings also suggest that better caregiving leads to parents being more satisfied with services, which, in turn, leads to less stress. These associations all highlight the value of providing services in ways that are family-centered and therefore meet parents’ needs for information, partnership, and support and understanding.

The most important predictor of parental well-being was child behavior problems. Most children's behavior problems were not severe, but their behavior was related to how much distress and depression their parents felt (also found by Quittner et al., 1990). Although child behavior problems predicted more depression and distress in our study, it is also conceivable that parents' depression may contribute to the higher reported incidence of behavior problems. The issue of reciprocal causation was not examined in the present study because it often results in technical problems in SEM (Hayduk, 1987). Furthermore, longitudinal data are needed to truly establish cause and effect.

Third, social-ecological factors (family functioning and social support) were a significant predictor of parents' well-being. This means that parents who are more satisfied with the social support they receive, and whose families are doing well, feel less stressed or depressed. The link between social support and well-being is well established for parents of children with disabilities (Quittner et al., 1990; Wallander et al., 1989c). To assist families, centers can provide practical assistance for informational and networking opportunities such as parent newsletters, parent resource centers, parent support groups, and drop-in centers. As for family functioning, service providers can assist families to develop problem-solving skills and coping skills and can encourage emotional expressiveness among family members.

General Clinical Implications

The emotional well-being of parents of children with disabilities was predicted better by parents' subjective perceptions and evaluations of life events (i.e., how they perceive caregiving, the behavior of their child, and the social support of others) than by demographic characteristics of the family (also see Wallander et al., 1989c). Service providers therefore need to be aware that parents' well-being is strongly influenced by the meanings parents give to others' behavior. Furthermore, parents' perceptions of caregiving, their children's behavior, and social support are all amenable to change.

The findings suggest that services will have the most benefits for parents when they address parent-identified issues, such as the availability of social support, concerns around family functioning, and child behavior problems, and are delivered in a family-centered manner. The key behavioral elements

of a family-centered approach are partnership between parents and professionals, supportive and respectful treatment, and information exchange (Rosenbaum et al., 1998). Furthermore, if managers want to increase parents' satisfaction with services, they may be well advised to pay attention to how services are delivered. This study indicates that parents are more satisfied when services are delivered in a family-centered manner.

Implications for Future Research

First, it would be wise to cross-validate the findings in an independent sample. Second, to truly establish the causal links that have been discussed, it is necessary to conduct a longitudinal study examining the factors affecting parents' emotional well-being. Third, it would be important to include data from other respondents in addition to parents.

It is interesting to look at the similarities and differences between our process-outcome model (containing prognostic indicators, professional caregiving, and mediating variables) and Wallander's model of factors that are risk-oriented or protective for parent well-being (Wallander et al., 1989c). Our model includes two constructs not examined by Wallander (professional caregiving and the outcome of satisfaction with care), treats stress as an outcome variable rather than a risk factor, and separates demographic variables from social-ecological factors. Wallander's model includes intrapersonal resistance factors and daily hassles. Since our model shows that child behavior problems and better professional caregiving (as well as better social-ecological factors) are associated with better outcomes, these variables should be included in future research. Moreover, studies refining these models of parent well-being should include variables specified by Wallander that are not in our model (i.e., intrapersonal resistance factors and daily hassles) and other variables such as intimate and extended family relationships (e.g., marital satisfaction).

In terms of associations between variables, there are several differences between the two models: (1) bi-directionality was not tested in our model but is part of Wallander's conceptual model; (2) coping has no direct effect on well-being in our model, but is hypothesized to have such an impact in Wallander's; and (3) we found no direct or indirect links from burden to adaptation (vs. Wallander's model). It is possible that the constructs of coping and burden were not well operationalized in our study. Fi-

nally, our structural model supports Wallander's by indicating that parameters of the child's disability are not a direct risk factor in predicting parent well-being, and social-ecological factors have a direct impact on well-being.

This study has implications for the use of SEM in pediatric rehabilitation research. Structural equation modeling allows researchers to examine complex relationships among a set of variables. It allows one to look at the importance of caregiving in the context of people's lives in a more comprehensive way than has been possible in the past. We need to evaluate comprehensive models to develop an adequate understanding of the factors affecting the well-being of parents of children with disabilities (Kazak, 1987; Wallander et al., 1989a). Only by truly understanding the experiences that affect parents' emotional well-being will we be able to meet parents' needs effectively and thereby improve outcomes for children.

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