

**Building a Model of Family Caregiving for
Children with Emotional Disorders**

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In this article we describe the results of an ongoing effort to better understand the caregiving process in families of children with severe emotional problems. We make two assumptions. First, we assume that these families are essentially like other families but are faced with a special challenge in raising and caring for their special children while at the same time performing the multiple tasks and demands faced by all families. Second, we assume that public policy and programs must be supportive of the care of these children in their own homes and communities whenever possible. The purpose of this article is to present a model of family caregiving that draws broadly from available theory and empirical literature in multiple fields and to subject this model to empirical testing. We use structural equation modeling with latent variables to estimate an empirical model based on the theoretical model. Results of the model testing point to the importance of the child's external problem behaviors and the family's socioeconomic status and coping strategies as determinants of caregiver stress. Other findings highlight difficulties in measuring and modeling the complex mediating process, which includes formal and informal supports, perceptions, and coping behaviors. The use of structural equation modeling can benefit out efforts to support families by making explicit out theories about the important dimensions of this process and the relationship between these dimensions, which can then be subjected to measurement and validation.

Families have been described as "the ecological system that nourishes the individual" (Zimmerman, 1980, p. 195) and as the primary "social service agency in meeting the social, educational, and health care needs" of members (Hartman, 1981, p. 10). There is wide agreement that families perform a number of functions for their members, including socialization, affection, economic sustenance, health care, domestic maintenance, recreation, and identification (Turnbull, Barber, Behr, & Kerns, 1988). Some families perform all these functions while contending with the ongoing stress of having a member with a disability, such as a child with an emotional disorder. A child with a serious illness or disability presents challenges to the caregiver; when a child requires extensive medical care, 24-hour supervision, and management of behavior, it is difficult for the caregiver to attend school functions important to other children in the family, have energy for paid work, spend enough time with other children in the family, maintain an intimate relationship, or even go grocery shopping.

The stresses and difficulties of caring for a child with a disability are reflected in the ways in which parents of children with emotional disabilities report that their lives are affected by their children's problems. In a large, national study of parents' perceptions of their needs and experiences with their children with emotional disabilities, more than half the parents surveyed said that their child's problems negatively affected family life in many areas (Friesen, 1989). Researchers have shown a relationship between children's emotional or behavioral problems and symptoms of parent or family distress. For example, family stress has been found to be related to family functioning in a dysfunctional range (Bernstein, Svingen, & Garfinkel, 1990); mothers' hostility toward their spouses and the spouses' aggressive response style (Johnson & O'Leary, 1987); families' high irritability and overprotection (McFarlane, 1987); and mothers' and fathers' depression (Brown, Borden, Clingerman, & Jenkins, 1988; Kaslow, Rehm, Pollach, & Siegel, 1988). Taken together, these correlational studies provide some evidence of a connection between children's emotional and behavioral problems and stress on parents and families.

With all the stresses families of children with disabilities encounter, however, some families do quite well. Indeed, some parents reported their lives to be positively affected by their children with emotional problems in areas such as involvement of both parents in caring for the child (Friesen, 1989). Most of the previous research on families with children with emotional disorders has paid little attention to aspects of families' lives in which they function well or to parental coping factors that differentiate levels of family adaptation and functioning (Early & Poertner, 1993). What is needed is an exploration of how parents cope with the stress and strain of caring for a child with emotional or behavioral problems and an investigation of the aspects of the social and physical environment that aid or interfere with coping.

Several researchers have suggested the use of an ecological or family systems model in the study of families with children with disabilities (Bubolz & Whiten, 1984; Crnic, Friedrich, & Greenberg, 1983). From a systems perspective, it is insufficient to study only the effects of the parents on the child or the child on the parents. Rather, it is necessary to study the various child, parent, family, and environmental factors that work together to influence the stress experienced and the outcomes produced. In other disability fields, families' experiences with

children with disabilities have been examined from a stress and coping standpoint (e.g., Crnic et al., 1983; Turnbull et al., 1986). Although this research has often focused on negative effects on the family of a child with a disability, more recent work has emphasized adaptation and coping strengths (Summers, Behr, & Turnbull, 1989; Behr, 1990). Attempts to understand how families respond to stress and why some families thrive despite stress are important in designing interventions that will assist families in caring for their children with disabilities.

A hypothetical model of family caregiving that incorporates the dominant conceptual models for understanding stress and coping is described in this article. The model attempts to explain variation in outcomes for caregivers and their children with emotional disorders, building on previous efforts to describe a family response to a crisis and an individual response to stress. The response process is characterized as consisting of antecedents, mediators, and outcomes. Antecedents are "givens" such as characteristics of the child, characteristics of the family, characteristics of the caregiver(s), and characteristics of the community in which the family lives. Potential outcomes include both positive and negative effects on caregivers' health and well-being, family functioning, and child functioning. Mediators (e.g., social services, social support, other internal or external resources) alter the effects on outcomes. The purpose of this article is to describe the findings from an empirical test of this model. By identifying antecedents and mediators that affect outcomes for families with children with serious emotional disorders, this article provides insights for targeting and designing more effective intervention and support strategies for these families.

Stress and Coping

Boss (1987) said that the systematic study of families facing trouble and disaster is relatively recent, dating to studies of the impact on families with sudden loss of income resulting from the Great Depression of the 1930s. Research of the next several decades focused on stressors such as the economic stress of living in a New York City slum (Koos, 1946) and family separation and reintegration because of fathers' and husbands' involvement in World War II (Hill, 1949). One of Hill's (1958) major contributions was formulating the ABCX Model for understanding family stress, in which Hill made explicit connections between the work of family sociologists on crisis-proneness and the research of social workers on multiproblem families. The ABCX Model focused on four elements: A, the stressor event; B, the strengths and resources the family has at the time of the event; C, the definition the family makes of the event; and X, the family crisis. The ABCX Model has been used extensively in research on families faced with a variety of stressors (McCubbin et al., 1980) and has undergone several revisions (McCubbin & McCubbin, 1987).

On the individual level, stress has been defined and studied as physiological (Selye, 1936, 1946), psychological (Lazarus, 1966; Lazarus & Folkman, 1984; Pearlin & Schooler, 1978), or social (Monat & Lazarus, 1991). Whether and how these three types of stress are related is unclear (Monat & Lazarus, 1991).

Although neither the sociological "family stress" theories nor the psychological "personal stress" theories exactly fit the situation of families with the chronic strain of caring for children with emotional disorders, a synthesis of these major approaches to the study of stress and coping may be useful for both research and practice. The conceptual model described next was developed through a review of empirical and theoretical literature of the stress and coping process and is a blend of these two approaches. (Development of the model is discussed in greater detail in McDonald, Poertner, & Donner, 1992). Starting with a focus on conceptual and operational definitions of major identified *mediators* in the stress process, the authors then looked backward to identify causal *antecedents* that might affect the stress process and then forward in an attempt to specify *adaptational outcomes* that capture desired end states in family caregiving. The Lazarus model and its use of systems thinking is most helpful in identifying these processes. However, one constraint in using the Lazarus model is that the family system is seldom considered. The focus on family is the major strength of the Hill (1949, 1958) model and the McCubbin et al. (1980) model, which provide more specific ways of thinking about the population of interest. In particular, research based on the family stress and coping models provides more applications dealing with chronic problems affecting children, the impact of these children on other family members, and the role of formal helping systems in this process.

Conceptual Model

The Family Caregiving Model is consistent with the approaches of both Lazarus (1966) and McCubbin et al. (1980) in that it identifies three major stages: antecedents, mediators, and outcomes. The model is depicted in Fig-

ure 1. Causality is expected to flow from left to right (i.e., antecedents to mediators to outcomes), with mediators interacting as diagrammed. Both direct and indirect effects of antecedents on outcomes are expected. Antecedents consist primarily of the child's characteristics, including both competencies and problem behaviors, as well as the family and caregiver characteristics, which help to define their responses to the special challenges presented in caring for children with emotional disorders. The model posits that these antecedents are mediated by both internal and external factors related to the family caregiver. External factors include the availability and use of formal (social services) and informal (social) supports. Internal factors include both cognitive and behavioral coping strategies used by the caregiver. Outcomes are considered to be the adaptational outcomes of the primary caregiver and the child with the disability (in part because of the difficulty of conceptualizing and operationalizing family-level variables). Categories of adaptational outcomes hypothesized by this model include caregiver social functioning, life satisfaction, and somatic health; family financial status; and child's living status, educational status, and participation in age-appropriate community activities. The central outcome, which is the focus of this article, is caregiver stress. The measurement of antecedents, mediators, and outcomes is discussed in the following sections.

Methodology

Procedure

Data were obtained from a survey of caregivers of children with serious emotional disorders. Caregivers were identified through the public mental health system in North Carolina. Children meeting the state's definitions of "atypical development" for preschoolers and "serious emotional disorder" for children 6 to 12 years of age were included in the study.

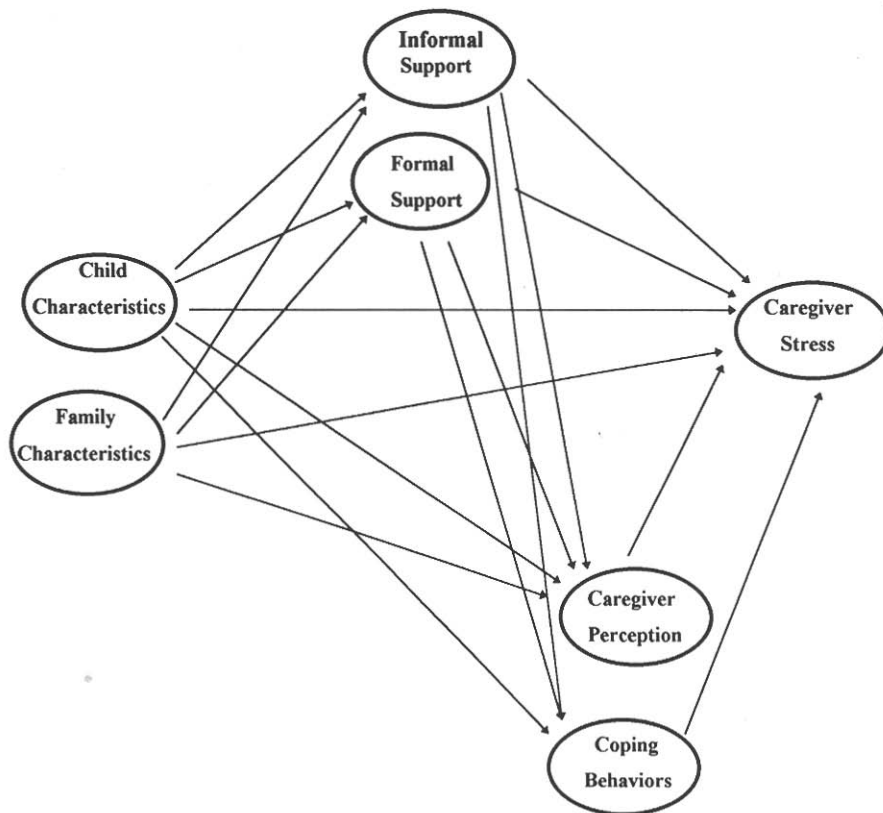


FIGURE 1. The Family Caregiving Conceptual Model.

To ensure confidentiality, families eligible for inclusion in the study had to be identified and initially contacted by state agencies. When a family agreed to be a part of the study, a research team based at the University of Kansas established direct contact with the family to compile a questionnaire. Purposive sampling was used to obtain adequate variation in the variables of interest in order to examine relationships among critical constructs identified in the Family Caregiving Model.

The first phase of the recruitment of families began with the identification of area mental health programs in North Carolina that would provide the diversity in service and population characteristics needed to adequately test the Family Caregiving Model. The criteria used to determine which area programs would be invited to participate were (a) population diversity (primarily race, urban/rural); (b) community service diversity; (c) identification of children in the 3-5 years age group; and (d) willingness to participate. The second step of sample selection was to establish contact with and get support from the regional child specialist in each of the four regions of the state; these specialists facilitated final agreements with agency administrators.

The family solicitation packet included a letter of support from the agency, a letter describing the project, and a card that was to be returned if the family was willing to participate. Following the suggestions of Dillman (1978) on conducting mail surveys, we asked the agency to send a reminder letter to each potential participant one week later. To ensure that the agency would not know which families agreed to participate, the caregiver was asked to return the agreement-to-participate card directly to the project staff at the University of Kansas. Approximately 1,800 family solicitation packets were sent to families in 18 counties covered by the 10 mental health area programs that agreed to participate. About one-fourth returned the agreement cards indicating a willingness to participate in the study. Of these, 108 were screened out due to age of the child. Fourteen families returned two cards for different children in the family; a decision was made to complete only one questionnaire for each family. Ultimately, questionnaires were mailed to 335 families. A total of 259 usable surveys were completed and returned, for a response rate of 77%.

Sample

Survey respondents were the primary caregivers for 259 children ages 4-12. Almost all the children (94%) were living at home at the time of the survey. In almost all cases (89%), the respondent to the survey was the mother of the designated child. The majority of the families had other children in addition to the study child. Approximately half of the families were headed by a married couple, while one third were divorced or separated single parents. Approximately half of the families reported that they lived in small or large cities (population 25,000 or more), whereas one fourth lived in towns of 2,500 to 25,000 people and another one fourth lived in small towns (population 2500 or fewer) or rural areas. The majority of respondents reported their racial or ethnic identification as White, and almost one third of respondents identified themselves as Black. More than 20% of the respondents had not graduated from high school. More than 40% of the respondents were employed full time, and slightly more than half of the respondents' partners were employed full time. One third of the respondents reported gross household annual income below \$10,000.

Measures

Child Characteristics. Measures of the child thought to be relevant contributors to caregiver stress included the gender of the child, age, and the child's problem behaviors and competencies. The child's competencies and problem behaviors were assessed by use of the Child Behavior Checklist/4-18 (CBCL; Achenbach, 1991), which was designed to be filled out by parents and parent surrogates. For these analyses, the Activities, Social, and School subscales were used to assess the child's overall competencies. Two subscales, Delinquent Behavior and Aggressive Behavior, were used to measure external problem behaviors, and internal problem behaviors were measured by the Withdrawn, Somatic Complaints, and Anxious/Depressed subscales. Achenbach (1991) reported that the inter-interviewer and test/retest reliabilities of the CBCL item scores were supported by intra-class correlations in the .90s and stability over a 2-year period. Interparent agreement was indicated by mean correlations ranging from .65 to .75. The instrument has been shown to discriminate significantly between demographically matched referred and nonreferred children and to correlate with numerous analogous scales.

A comparison of our sample with referred and nonreferred samples provided by Achenbach (1991) showed our sample to be significantly different from his nonreferred, but similar to his referred, samples. The boys in our

sample were found to have lower total competency scores and higher problem scores on each subscale and summative scale (Internalizing, Externalizing, and Total Problems). The girls in our sample were more nearly identical to Achenbach's sample of referred girls. The study sample of girls, however, scored significantly higher on delinquent and aggressive problem behaviors, resulting in significantly higher summative scale scores for Externalizing and Total Problems.

Family/Caregiver Characteristics. Characteristics of the family included income, number of other children living in the house, age of oldest child, and age of youngest child. Characteristics of the primary caregiver included marital status, race, education, employment, and age.

Social Support. Two widely used subscales of the Family Index of Regenerativity and Adaptation-General (FIRA-G; McCubbin & McCubbin, 1987) were included in the survey instrument. The dimensions measured are Relative and Friend Support (8 items) and Social Support (17 items), where higher scores are indicative of more social support. Scores for these two scales for the study subjects were compared to a normative sample of families with preschool and school-age children provided by McCubbin and McCubbin. Scores on the Relative and Friend Support scale are nearly identical for the two samples (25.0 and 25.9, normative and study sample, respectively); however, the sample of caregivers of children with serious emotional disabilities had significantly lower reported social supports than the normative sample (39.1 and 45.3, respectively). Both scales had reliability coefficients above .70 for our sample.

Formal Supports. The scales for measuring the parents' experience with the formal support system were adapted from an instrument developed by the Research and Training Center at Portland State University. These instruments do not provide normative data and have not been widely used elsewhere. The Professional Collaboration Scale consists of 12 items reflecting different aspects of a more collaborative style of professional-client interaction (e.g., professional asked for your opinions, treated you as an asset in the child's treatment, was sensitive to your cultural/ ethnic background). The scale was found to have high inter-item reliability for these data ($\alpha = .86$).

The Service Utilization Scale consists of 19 different types of services (e.g., special education classroom, social worker, psychologist, day treatment) likely to be used by families with children with serious emotional disorders and an additional category for specifying other service types. The scale score used here is the number of services ever used.

Coping Behaviors. We have relied on the Coping Health Inventory for Parents (CHIP) developed by McCubbin & McCubbin (1987) because it has been used extensively to measure coping patterns of families caring for a chronically ill member. CHIP provides three subscales, labeled Integration, Cooperation, Optimism; Support, Esteem, Stability; and Medical Communication and Consultation. Higher scores on the Coping Scales indicate greater use of the coping pattern.

Perception of Child. The current study measured perception by utilizing the Positive Contribution Scale (Summers, Behr, & Murphy, 1991) and the six items (Positive Outlook Scale) identified as measuring perception within CHIP (McCubbin & McCubbin, 1987). The Positive Contribution Scale is noteworthy in that it operationalizes new thinking in this field that moves away from a focus on negative aspects of care, giving to measure the parent's perception regarding the positive contribution of his or her child to the parent's life and development. The scale consists of 53 items, which can be grouped into 9 subscales reflecting the extent to which the parent views the child as a source of happiness and fulfillment, expanded social network, strength and family closeness, awareness of future issues, learning through experience with special problems in life, understanding of life's purpose, pride and cooperation, personal growth and maturity, and career and job growth. Subscale scores reflect the caregiver's level of agreement with statements concerning the positive contribution of the child. The higher the score, the greater the agreement.

Caregiver Stress. The stress measure used was developed by Press (1989). This measure consists of 13 life areas such as job, caring for home and family, physical health, and life in general; it asks respondents to rate the degree of stress on a 6-point scale from none to high or extreme amount of stress. In terms of reliability, Press reported coefficient alphas for this instrument ranging from .70 to .93, with a median value of .86 (Press, 1989). In this study the scale demonstrated a reliability coefficient of .87. In terms of evidence for validity of the scale, Press reported a correlation of .63 between his scale and Hudson's Index of Clinical Stress (Press, n.d.). Responses to the

stress items indicated that this sample of caregivers of children with serious emotional disorders experienced moderate to high stress levels overall, with the highest stress reported in the domains related to caring for home, family, and children.

Analysis

Covariance structure analysis was used to estimate a structural equation model based on the family caregiving conceptual model described earlier. The analysis was performed using the EQS Structural Equations Program software (Bentley, 1992). In structural equation modeling, it is necessary to specify how we think underlying latent variables or constructs (e.g., disturbed behaviors, coping, caregiver stress) are related to one another in a causal or explanatory way. This is the purpose of a conceptual model such as the one shown in Figure 1. However, structural equation modeling with latent variables requires researchers to be much more explicit. Latent variables involve more complex theoretical concepts that are more difficult to directly measure or observe. However, often a number of indicators or direct measures can be used to represent the latent variables. Structural equation modeling requires that researchers also specify how they believe the direct measures or observed variables relate to these underlying constructs or latent variables. Structural equation modeling then requires the specification and estimation of both a measurement model and a structural model. Its main advantage is that measurement concerns become integrated with model development, estimation, evaluation, and interpretation (Hayduk, 1987). In this way, it differs from multiple regression approaches, which require the unreasonable assumption of perfect measurement.

In the absence of adequate tools for measuring the underlying constructs, meaningful estimation of structural relationships between constructs is impossible. This was the first challenge in constructing a structural equation model that would allow testing of the theoretical model for family caregiving. Despite having used many widely accepted scales to measure the constructs of the caregiving model, our initial attempts to replicate the factorial structure (subscales) of these scales through the use of confirmatory factor analyses revealed a very poor fit (see Note 1). This led us to conclude that, in general, the more complex structures suggested by the authors of these scales were not supported by our data. Simplification and improved fit were obtained by selecting items from single-dimension scales with the highest reliability and by using subscale scores—which combine items into a single score—as indicators for unitary constructs for scales that had multiple subscales (see Note 2). A list of each of the broad conceptual groupings (e.g., informal problem behaviors, social support, coping) identified in the Family Caregiving Conceptual Model are given in Table 1. Under each of these groupings are listed the latent variables and the specific indicators used for each latent variable.

Results

The initial structural model tested with EQS included all latent and observed variables shown in Table 1. This model included all paths or structural equations implied by Figure 1, where, moving from left to right, paths were drawn to all succeeding variables. Due to the large number of variables, constructs, and paths involved, this initial model was very difficult to represent graphically and is not shown here. The large number of paths in the initial model reflects, for the most part, a lack of sophistication in our existing theory and research. That is, based on current understandings of the caregiving process, it is difficult to exclude, a priori, the possible effect of any preceding variable on subsequent process or outcome variables. As expected, however, simplification of the initial model was not only possible but necessary for convergence to a unique solution.

The most serious problem encountered in the attempt to estimate the initial model involved the latent antecedent variable, which attempted to capture Family Composition as measured by the observed variables Marital Status, Number of Other Children in the Family, and Age of Youngest Child in the Family. None of the paths from this to other constructs were significant, which led us to drop this construct from the model. With the omission of this construct, convergence was obtained; however, there was considerable lack of fit in the model with fit indices fluctuating around .800. Diagnostic statistics provided through the Wald test suggested that several parameters that were treated as free in the model could be set to zero (i.e., paths could be eliminated). We then began to trim the model, eliminating nonsignificant paths one at a time. This process led to the elimination of two additional constructs related to the measurement of Formal Support (Professional Collaboration and Number of Services Used).

The final structural model, showing only the significant relationships between constructs, is displayed in Figure 2. The reader can judge the fit of the measurement model from Table 2, which displays the loadings of individual indicators on corresponding constructs. These loadings are quite high, with the majority being over .60. The overall fit obtained with this model could be judged as fair (Bentler-Bonett normed fit index = 0.810; nonnormed fit index = 0.897; comparative fit index = 0.911). In this model-trimming process, we were guided by both empirical and theoretical considerations. This final model is described in the following sections, first in terms of its performance in explaining the primary outcome of caregiver stress. We then focus on the other endogenous variables that were hypothesized to describe the mediating process of family caregiving. In reviewing these findings, the reader should remember that the analysis performed here was highly exploratory and involved the use of cross-sectional, correlational data. Reliance on these findings in formulating strong causal statements about relationships among the studied constructs would be inappropriate.

Caregiver Stress

Overall, the model explained 27% of the variance in caregiver stress. Only three of the latent variables were found to make a significant direct contribution to caregiver stress. In Figure 2, these contributing variables can be identified by tracing paths that lead directly to Caregiver Stress (F9). The numbers appearing on these paths are standardized regression coefficients that can be used to judge the direction and relative contribution of each variable. The three variables contributing to caregiver stress in the model are, in descending order of importance, Child's External Problem Behaviors (.45), Family Socioeconomic Status (.19), and Coping Behaviors of the Caregiver (-.12).

The child's external problem behaviors are clearly the largest influence on caregiver stress. This occurs primarily as an unmediated effect of the problem behaviors on caregiver stress. In addition, external problem behaviors indirectly affect caregiver stress through family support and coping behaviors. Increases in external problem behaviors reduce Relative and Family Support (F5), which in turn reduces Coping (F8), which leads to increased caregiver stress. On a more positive side, the child's competencies appear to play a role, albeit relatively small and indirect, in reducing caregiver stress. Increased Competence (F3) appears to enhance Social Support (F6), which in turn increases Coping (F8) strategies available to the caregiver, which reduces stress.

The families' socioeconomic status (gross income, caregiver's educational level and employment) can also be seen to have a direct effect on caregiver stress that is not mediated by any of the variables identified in our model. Higher socioeconomic status is associated with increased levels of caregiver stress. Socioeconomic status also affects caregiver stress indirectly through Relative and Family Support (F5) and Coping (F8). Higher socioeconomic status is associated with lower support from friends and families, which leads to decreased coping strategies and increased stress. Of the mediators, only coping was found to directly influence caregiver stress. Greater use of coping strategies was associated with decreases in caregiver stress.

Mediators

As noted previously, of the first-stage mediators (Formal and Informal Supports), only Informal Supports was retained in the final model. The family's Socioeconomic Status (F4) can be seen to influence both the support available from Relatives and Family (FS) and broader Social Support (F6). However, the effect is the opposite for each. Higher socioeconomic status is associated with decreased levels of support from relatives and family but with increases in social support in the community.

Of all the endogenous variables, the model is most successful at explaining variance in the caregiver's perception of the child as a source of Positive Contributions (F7). Perceptions of the child as being a source of positive contributions to the family are supported by enhanced support from Relatives and Family (FS) and Social Support (F6) as well as by greater Competence (F3). However, higher Socioeconomic Status (F4) is associated with less positive perceptions of the child.

In that Coping (F8) is the only mediator to have a significant direct impact on caregiver stress, factors contributing to increases in coping strategies are of particular interest. From the model, it appears that increases in informal support (both Relative and Family Support [FS] and Social Support [F6]) can enhance coping strategies.

Table 1. Latent and Observed Variables

Child characteristics

1. Internal problem behaviors
 - a. Child Behavior Checklist (CBCL) Withdrawn subscale
 - b. CBCL Somatic Complaints subscale
 - c. CBCL Anxious/Depressed subscale
2. External problem behaviors
 - a. CBCL Delinquent Behavior subscale
 - b. CBCL Aggressive Behavior subscale
3. Competencies
 - a. CBCL Activities subscale
 - b. CBCL Social subscale
 - c. CBCL School subscale

Family characteristics

1. Socioeconomic status
 - a. Gross Family income
 - b. Caregiver's educational level
 - c. Caregiver employed
2. Family composition
 - d. CBCL Activities subscale
 - e. CBCL Social subscale

Informal support

1. Relative and family support
 - a. Seeking advice from relatives
 - b. Sharing our difficulties with relatives
 - c. Asking relatives how they feel about the problems we face
2. Social Support
 - a. Friends who let me know they value who I am and what I can do
 - b. Very close friends outside the family whom I know really care for me and love me
 - c. People who depend on each other

Formal support

1. Professional collaboration—Has the professional with whom you've been most involved:
 - a. Felt that your view of your child has been useful in making decisions about treatment?
 - b. Included you and your family in defining goals for your child?
 - c. Treated you as a valuable asset in your child's treatment?
2. Number of services ever used.

Perception

1. Positive contribution
 - a. Child is perceived as a source of strength and family closeness
 - b. Child is perceived as a source of personal growth/maturity
 - c. Child is perceived as a source of expanded social network
 - d. Child is perceived as a source of increased pride and cooperation

Coping behaviors

1. Maintaining family integration, cooperation, and an optimistic definition of the situation
2. Maintaining social support, self-esteem, and psychological stability
3. Understanding the medical situation through communication with other parents and consultation with medical staff.

Caregiver stress

1. Caring for home and family
2. Family relationships other than marriage or primary relationship
3. Caring for child or children

Note. CBCL=Child Behavior Checklist (Achenbach, 1991).

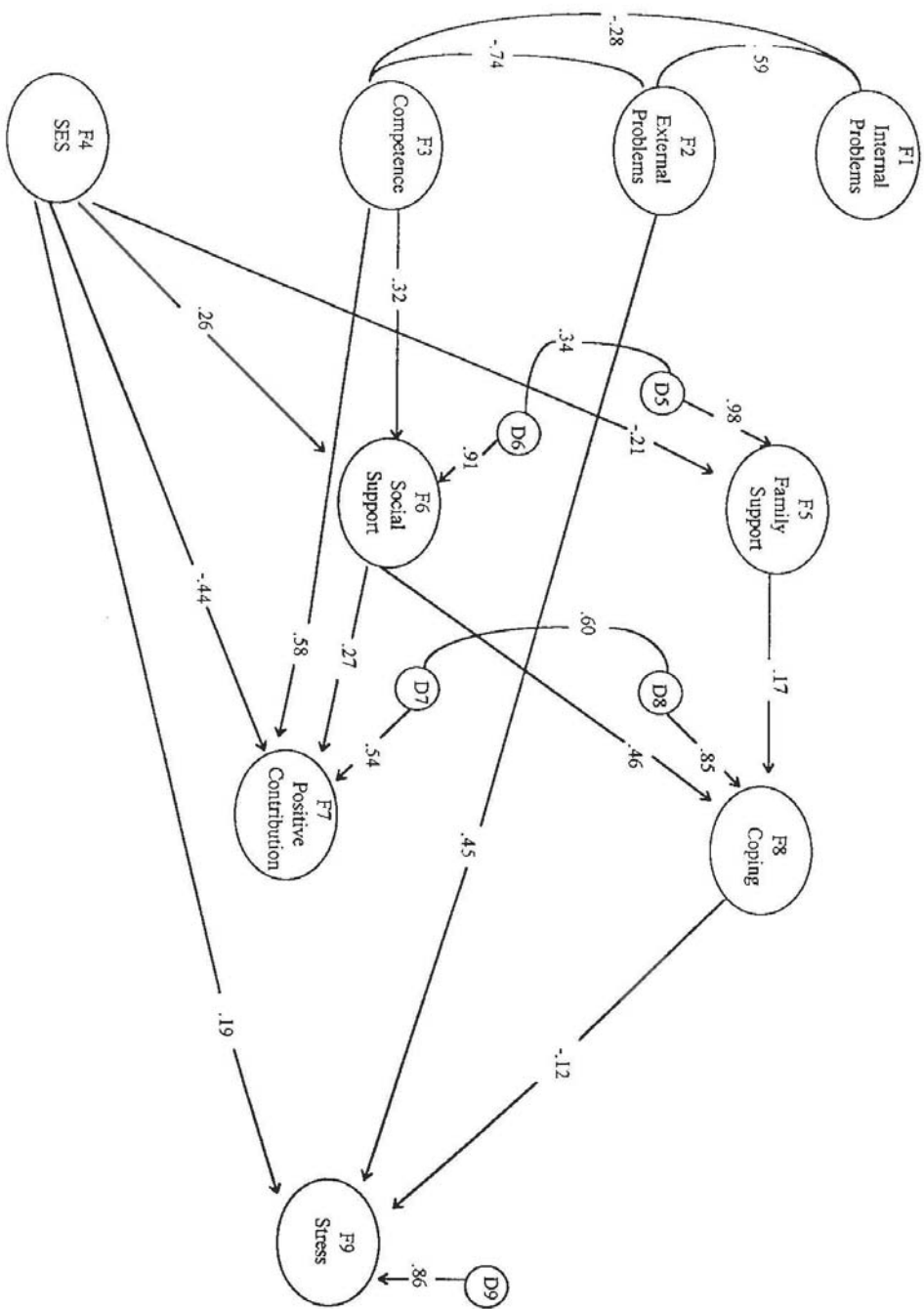


Figure 2: The final structural model.

Table 2
Constructs and Indicator Loadings

Construct	Indicators	Loading
Internal problems	CBCL Withdrawn scale	.74
	CBCL Somatic scale	.59
	CBCL Anxious/Depressed scale	.89
External problems	CBCL Delinquent scale	.70
	CBCL Aggressive scale	.43
Competence	CBCL Activity scale	.38
	CBCL Social scale	.68
	School scale	.32
Socioeconomic status	Income	.70
	Caregiver education	.65
	Caregiver employed	-.45
Family support	Seek advice from relatives	.51
	Ask relatives about problems	.51
	Share difficulties with family	.62
Social support	Friends who value me	.53
	Close friends who care	.63
	Can depend on community	.49
Positive contribution	Strength scale ^a	.60
	Growth scale ^a	.59
	Social scale	.70
	Pride scale	.76
Coping	CHIP: Maintain family scale	.70
	CHIP: Support esteem scale	.68
	Chip: Understanding scale	.73
Stress	Stress in maintaining home	.80
	Stress in caring for family	.50
	Stress in caring for child	.90

Note. CBCL = Child Behavior Checklist (Achenbach, 1991); CHIP = Coping Health Inventory for Parents (McCubbin & McCubbin, 1987).

^a These variables had errors correlated at .36.

Implications

Families currently serve as the primary caregivers of children with chronic illnesses or disabilities. Social values, the desires of the children and their parents, and pragmatic considerations (e.g., cost, availability of placements) dictate that professionals continue to look to families to serve in this caregiving function. These families are locked in a process that seeks to maintain family stability and maximize the well-being of individual family members. If professionals are to work with families in an effort to enhance these outcomes, the professionals must have a better understanding of the family caregiving experience. This understanding must be deeper than that provided by descriptive data, regardless of the richness of our theories and descriptions. The ultimate concern and purpose of understanding the family caregiving process is causal in nature. The rationale for the professional's role is to make things better, to support the family in its caregiving process. To do this we must focus on and come to better understand the causal processes at work.

The purpose of this article is to propose and test a conceptual model of the process of family caregiving for a child with a chronic illness or disability. To that end, we have attempted to refine and build on existing models in family sociology and cognitive psychology and to incorporate findings from empirical research into building the Family Caregiving Model. Salient features of this model and principles that have emerged from our review include the following:

- The caregiving process must be conceptualized into three distinct stages: antecedents, mediators, and outcomes.
- Clear distinctions must be made between the mediating process and the resulting outcomes for the family.
- The mediating process involves emotion, cognition, and behaviors, which, while conceptually distinct, involve a highly interactive process that is difficult to disentangle. Separation of cognitive and behavioral responses are possible, however, and can lead to a better understanding of caregiver stress and coping.

- Presently, caregiving outcomes can best be conceptualized and measured by focusing on the primary caregiver (usually the mother) and the child. Outcomes for the child should focus on maintenance and integration in the home and community.

One of the major challenges faced in conducting this research was the relative lack of specificity in existing theory. As mentioned previously, many existing measures are not adequately grounded in any theory. Much work remains to be done in developing valid and reliable measures, and we believe that this work should be guided by a clear conceptual model of the caregiving process. It should also be recognized that most of the existing scales that can be used for measuring the constructs identified in our model have only been subjected to one-time exploratory factor analyses. Replication studies that apply newer confirmatory factor analysis techniques are needed to refine these scales. A major advantage of the structural equation modeling approach used in this article is that, unlike regression models, which assume no measurement error, the structural equation model makes explicit both a measurement and a structural model that are subject to testing. However, if the measurement model does not achieve reasonable fit, it is impossible to proceed to estimate a structural model under the illusion that we know how to measure the constructs of our model. If ignorance is bliss, increased awareness can also be agony for the researcher.

The Family Caregiving Model for families with children with serious emotional disorders, which is described in this article, should be viewed as a first step in the process of using theory, measurement, and empirical evidence to better understand this process. The final model presented here is by no means final and should be subjected to further scrutiny both conceptually and empirically with new data. Nevertheless, this analysis does provide some preliminary findings that the field should view with interest and caution. This model suggests that, from the perspective of the primary caregiver, the child's external problem behaviors are difficult to mediate and directly contribute to increased levels of stress. Although this finding focuses attention on the need to find ways to buffer caregivers from the stress associated with the child's external behaviors, it should be stressed that the lack of influence of internal problem behaviors does not imply that they can be ignored. From the perspective of other family members and interested parties (e.g., the child, a mental health professional) or other outcome measures (e.g., the child's adjustment as an adult), the child's internal problem behaviors might assume greater importance.

Enhancement and recognition of the child's competencies should also not be ignored. The findings presented here suggest that increases in competence are directly associated with increases in social support and the perception of the child as making a positive contribution to the family as well as indirectly enhancing coping strategies and reducing caregiver stress.

The findings involving the socioeconomic status of the family also deserve discussion. This construct was originally included with the expectation that it would serve as a measure of family resources that could be expected to facilitate the caregiving process. Our findings suggest a much more complicated relationship. Overall it appears that higher socioeconomic status is more likely to be associated with increased caregiver stress, less positive perceptions of the child, and less support from relatives and family. Recognizing that higher socioeconomic status for our sample is achieved primarily through the employment of the caregiver may help to explain this effect. The demands of work outside the home and caring for a child with special needs undoubtedly place extreme pressure on relationships within the family that focus on the caregiver. It should be noted, however, that work outside the home also increases the caregiver's sense of broader social support from friends and the community. Interventions must be designed to allow the caregiver to receive this external support without losing support within the home of family and other relatives, which might contribute to perceptions of the child as a burden.

The relatively weak performance of the hypothesized mediators of caregiver stress does not necessarily mean that they are unimportant. Improvements in the measurement of these constructs alone could lead to greater explanatory power. However, some rethinking of these constructs and their role may be warranted. In developing our conceptual model, we have argued that the field has suffered from a failure to put outcome before process. Much of the stress and coping literature, both in sociology and psychology, has suffered from a circularity that fails to separate outcomes from the process that generates these outcomes. The construct of "coping" provides an example of this where the word can imply both mastery (coping as an outcome) and specific behaviors designed to achieve stress reduction (coping as a response process). In the research reported here, we have evidence that coping strategies are directly related to caregiver perceived stress, whereas social support and perceptions of the child are not. The potential role and usefulness of these latter constructs must be reconsidered in terms of how they might relate to other outcomes of interest or how one might try to justify their continued importance as actual outcomes.

themselves. For example, it is not difficult to imagine a mother who has strong social support and positive perceptions of her child but still feels highly stressed. Social support may be found to play a larger role in keeping the child in the home and actively involved in the community. We may believe that a positive perception of the child is important in and of itself. In either case, it is unlikely that we would consider the caregiver to be better off with no social support or with negative perceptions of his or her child. However, the modeling process we have just gone through forces us to rethink the caregiving process and the outcomes we are striving to achieve and to make these judgments explicit.

Finally, we must reiterate that this work can be viewed only as a step in the ongoing attempt to better understand and support families in caring for their children with serious emotional disorders. Our own attempts here have been limited by our ability to measure complex constructs and to collect adequate data from the families themselves. We ourselves have thought of more complex models involving additional constructs that we would like to test. For example, the current model excludes community-level variables and additional characteristics of the child (notably age and gender) that should be considered. Ideally the model should be run separately for males and females, and perhaps for different age groups, to determine whether a different structure exists for each. Such tests are possible with structural equation modeling; however, our sample was not large enough to support this type of testing. Our data are also limited to one perspective, that of the primary caregiver, at one point in time. Ideally multiple perspectives would be incorporated into the data collection over time. But no single study can answer all questions about the highly complex family caregiving process. The main contribution of this article to this effort is as a demonstration of a broader, more comprehensive conceptualization of the caregiving process and of an analytic technique that can provide empirical testing of alternative specifications of the caregiving process.

Authors' Notes

1. Tests of the measurement model led the authors to prepare a critique of the scale structure used by Achenbach to measure child problem behaviors. For further discussion, see McDonald and Gregoire (1995).
2. The use of subscales, which combine items from a scale, as indicators of a unitary construct had the added advantage of improving the distributional properties of these indicators since scale items were usually answered with Likert-type response categories, some with as few as three response categories.

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