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Interrelationships Among Variables Affecting Well Siblings and Mothers in Families of Children With a Chronic Illness or Disability

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A structural equation model (SEM) examined interrelationships among psychosocial variables known to affect the health and development of well siblings and parents when a child with a chronic illness or disability is a member of the family. Using dyads of 252 well children and parents, socioeconomic status (SES) and family cohesion were associated with the parent-reported behavior of the well sibling. SES also influenced the mood of the mother that in turn influenced family cohesion. The well sibling's knowledge about the illness of the brother or sister, attitude toward the illness, mood, self-esteem, and feelings of social support were interrelated and related to the behavior of the well sibling. The SEM suggests that interventions may be directed at several points in these interactions including boosting knowledge levels of the well sibling,

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improving family cohesion, and assuring adequate "income" support to the family through income transfers or in-kind services.

KEY WORDS: pediatric chronic illness or disability; cognitive and psychosocial outcomes; child development; family systems theory; structural equation modeling.

INTRODUCTION

Siblings in families with a brother or sister who is chronically ill or disabled have been reported to be at risk for a number of adverse health and psychosocial outcomes; Williams (1997) has reviewed this literature. Stein and Jessop (1989) have found that siblings and families with different chronic illnesses face many common difficulties and challenges within the family. These difficulties include long-term caregiving burdens, strains on family resources (financial and emotional), and interaction and communication problems within the household (Breslau and Prabucki, 1987; Hobbs and Perrin, 1985; Stein and Jessop, 1989; Williams *et al.*, 1999). Both Williams and Stein and Jessop suggest a "noncategorical approach" to service to these families because of common problems faced regardless of illness categories or diagnoses. Unfortunately, a relatively small number of studies of well children in these challenged families have been reported, and these studies concentrate largely on an enumeration of risk and protective factors. Interrelationships among these factors and their combined effects on the well child have been little studied in this family setting.

Structural equation models (SEMs) have been suggested as an alternative to single equation models or traditional analysis of variance techniques to study such multifactorial situations (Moody *et al.*, 1990; Williams and DeLurgio, 1994). However, appropriate use of SEM requires the specification of a model to be tested before the research is undertaken. Therein lies a problem. Many relationships among variables that can affect a health state have not been previously tested, complex relationships that have been tested often produce ambiguous or conflicting findings, and much work in this area must be considered exploratory because of the lack of universally accepted models. Nevertheless, exploratory models can be helpful.

For example, path analyses of siblings and mothers of children with a chronic illness by Williams *et al.* (1999) done with modest statistical power nevertheless showed strong relationships among maternal mood, family cohesion, positive sibling mood, and sibling feelings of social support and self-esteem. A study by Graff (2001) also showed strong relationships among greater sibling knowledge about the illness, more positive attitudes toward the illness and illness impacts on the self and family, and more positive mood. Almost 30% of the variance in sibling attitude was accounted for by sibling knowledge about illness.

These findings and others in the literature were helpful in defining the SEM model fitted in this paper. Additionally, enough findings have been accumulated by a single group of researchers to justify an SEM using some key variables (Williams and Williams, 2000). This model is being used to assess an NIH-funded intervention provided to well siblings and parents of children with chronic illness or disability. Data used in this paper to "test" the structural equation model presented in Fig. 1 were obtained at baseline from subjects in this larger longitudinal study.

STUDY PURPOSE AND HYPOTHESES

The purpose of this study is to assess simultaneous relationships among eight variables using the SEM presented in Fig. 1 and the previously

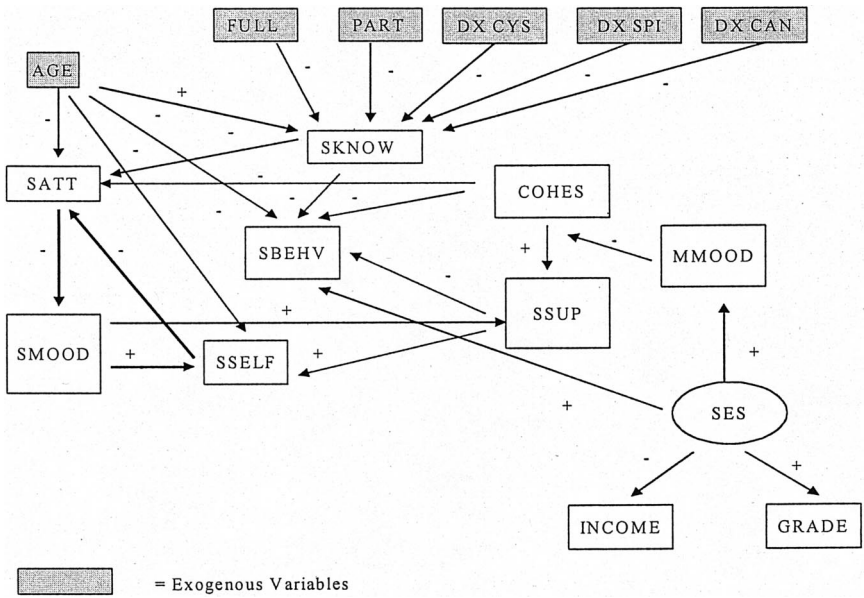

Fig. 1. Hypothesized Structural Equation Model (Baseline). (1) SKNOW = Sibling Knowledge about Illness, (2) SMOOD = Sibling Mood, (3) SATT = Sibling Attitude towards Illness, (4) SSELF = Sibling Self-Esteem, (5) SSUP = Sibling Social Support, (6) SBEHV = Child Behavior Problem, (7) MMOOD = Parent Mood (8) COHES = Family Cohesion, (9) AGE = The chronological age of the sibling reported at data collection, (10) FULL = Full treatment group, (11) PART = Partial treatment group, (12) DXCYS = Cystic fibrosis, (13) DXSPI = Spina bifida, (14) DXCAN = Cancer, (15) DXDIA = Diabetes, (16) DXDEV = Developmental disabilities, (17) SES = Socioeconomic Status, (18) INCOME = Annual family income, (19) GRADE = Education of the parent.

mentioned data. The eight study variables and others included as covariates are more fully described below.

Arrows indicating the direction of hypothesized linkages are shown in Fig. 1. Positive and negative relationships are shown with a "+" or "−" sign, and are consistent with the literature. The signs shown in the figure reflect both the hypothesized relationship and the direction of measurement assigned by the study instruments.

METHODS

Sampling: Sites and Subjects

The study was done at a large center contiguous to two states in the Midwestern United States. Approval by the Institutional Review Boards of the study sites and informed consents were obtained. A sample of 252 pairs of parents and siblings of a child with a chronic illness or disability was included in this study.

Parents were approached through clinical contacts at two hospitals and several community agencies for voluntary participation. The parents had a child with one of four chronic illnesses (cancer, cystic fibrosis, diabetes, or spina bifida) or a developmental disability (e.g., autism, seizure disorder, cerebral palsy, etc.). After agreements to join the study had been obtained, dyads of parents and siblings were randomly assigned to treatment groups. If there were more than one sibling in the family, the sibling included in the study was the one closest in age to the ill child. The data used in this paper are those collected at baseline before any intervention was provided. Thus, except as noted below, the parent–child pairs can be treated as members of a homogenous group of subjects.

Sample Characteristics

The mean age of the 252 study siblings was 11 years. About two thirds were older than the ill child, 50% were male, and 86.1% were Caucasian, while the rest were African American (4.4%), native American (2%), Hispanic (1.2%), Asian (0.8%), and biracial (5.6%). Most of the children (82.1%) lived in two-parent families. Most families (60%) had mean annual incomes in the range of $40,000–49,000 or above. Most (69.5%) of the parent respondents either had some training beyond high school or were college graduates. Thus, the study subjects had higher incomes, socioeconomic status (SES), and less minority representation than would

be found in many situations, which is a significant limitation of this study.

The mean age of children with chronic illness or disability was 9.5 years. These children had diagnoses of developmental disabilities (42.5%), diabetes (34.5%), spina bifida (9.5%), cancer (8.7%), or cystic fibrosis (4.4%).

Forty subject dyads (14%) indicated intent to join the study, but did not show at baseline or later left the study. These subjects did not differ statistically from those remaining in the study on any of the variables mentioned.

Variables and Measures

The 16 variables listed below were used to fit the path model. These include eight study variables and six covariates. Two additional variables, income and education, were used to construct a latent variable measuring SES. These variables were frequently mentioned in the literature reviewed. The eight study variables are as follows:

(1) *Sibling Knowledge About Illness (SKNOW)*: This variable was measured by the Knowledge Test (KT), a 30-item test of the knowledge of the sibling about the brother' or sister's chronic illness or disability (either cancer, diabetes, cystic fibrosis, spina bifida, or developmental disabilities). Questionnaires were pilot-tested on siblings and the ill children themselves. The K-R 20 of the tests ranged from 0.85 to 0.88. A high score on the test indicates greater knowledge about the illness of the ill brother or sister.

(2) *Sibling Mood (SMOOD)*: This variable was measured by the Sibling Perception Questionnaire—Revised—Mood Scale (SPQ; Sahler and Carpenter, 1989). The revised tool was used to assess sibling mood, or affective responses to the illness experience within the family context. This scale has a reported Cronbach's alpha of 0.86 In this study, the alpha coefficient was 0.76. A high score indicates self-reported positive mood.

(3) *Sibling Attitude Towards Illness (SATT)*: The SPQ-Attitude Scale measured this variable; the tool has 23 items that reflect sibling self-reported attitude toward (or perception of) the illness and its impact on the self and the family. The same 5-point Likert scale response choices are used, as in the SPQ-Revised—Mood Scale. In this study, the internal consistency reliability of this scale was 0.80. A high score indicates a more negative attitude toward (or perceptions of) the illness or disability.

(4) *Sibling Self-Esteem (SSELF)* was measured by the Self-Perception Profile for Children (Harter, 1985b). Construct, convergent, and discriminant validities have been established. In this study, the total scale alpha coefficient was 0.91. High scores indicate self-reported high self-esteem or self-perception.
(5) *Sibling Social Support (SSUP)* was measured by the Social Support Scale for Children (Harter, 1985a), answered by the siblings. Harter defines social support as the positive regard from others (parents, teachers, classmates, and close friends). Construct and concurrent validities of the scale have been demonstrated (Harter, 1985a). In this study, the alpha coefficient was 0.85. High scores indicate high self-reported social support.
(6) *Child Behavior Problem (SBEHV)* was measured by the Eyberg Child Behavior Inventory (Eyberg and Robinson, 1983), answered by parents. Scales have 36 items listing typical problem behaviors of children 2–16 years old. To validate the parent report, a corresponding teacher report form also was used. The correlation between the parent and teacher reports in this study was $r = 0.36$, $p < 0.001$. Both scales are appropriate for a community sample, such as the one used in this study. The internal consistency coefficient for the inventory in a nonreferred (i.e., nonill) sample has been reported to be 0.98. In this study, the alpha coefficients of the scales exceeded 0.95. A high score on the inventory reflects greater problem behaviors of the child.
(7) *Parent Mood (MMOOD)* was measured by the Profile of Mood States—Short Form (POMS-SF; McNair *et al.*, 1992). Answered by a parent, the scale is an established measure of mood disturbance. Construct validity of the POMS has been demonstrated. The alpha coefficient of the scale in this study was 0.94. High scores on the POMS indicate more negative mood.
(8) *Family Cohesion (COHES)*: The Family Adaptability and Cohesion Scales (FACES II) was used to assess family cohesion and adaptability by self-report (Olson *et al.*, 1985). The scales are appropriate for families across the life cycle. Items are readable and understandable at the 12-year old level. Numerous studies have shown the ability of the scales to discriminate between nonproblem and problem families in predicted directions. Internal consistency is 0.77, and 1-month test-retest reliability is 0.83 for the cohesion subscale as reported in past studies. The alpha coefficient of the cohesion subscale used in this study was 0.86. A high score indicates high, parent-reported family cohesion.

The six covariates are as follows:

(1) AGE is the chronological age of the sibling reported at data collection.
(2) and (3) FULL and PART are indicator (0,1) variables marking whether a subject was placed at baseline in the full treatment group, partial treatment group, or by implication in the control group (CONTROL). Although as noted previously the data used in this study were collected at baseline before any intervention or treatment, these indicator variables were used to correct for any possible biases in the recruitment of subjects for treatment groups. Such biases may arise when subjects are recruited from different institutions over a period of time (Levy and Lemeshow, 1991).
(4–6) The diagnoses of the ill child were indicated (0,1) to be cystic fibrosis (DXCYS), spina bifida (DXSPI), cancer (DXCAN), or by implication either diabetes (DXDIA) or developmental disabilities (DXDEV). Siblings in families with the three diagnoses used as indicators were observed to have significantly lower measured knowledge about illness scores compared to siblings in families with the two other diagnoses.

The two variables used to construct the latent measure of SES are as follows:

(1) Annual family income or INCOME was measured as eight categories ranging from "less than $10,000" to "more than $75,000." A higher category number indicated a higher income.
(2) Education of the parent (GRADE) answering the questionnaires and accompanying the child, in almost all instances the mother, was measured as six categories ranging from less than seventh grade to a graduate degree (i.e., a degree beyond the bachelor's). A high category number indicated a lower level of education.
(3) SES is the latent variable obtained from INCOME and GRADE. Because of the signs of the two endogenous variables and in the procedure used to fit the SEM, a high SES score reflects low SES.

SEM Methods

The eight study variables mentioned previously were used in the SEM. These included the knowledge about illness scores of the siblings (SKNOW), the attitude of the sibling toward the illness (SATT), the mood of the sibling (SMOOD), the self-esteem of the sibling (SSELF), and the social support felt by the sibling (SSUP). Three other variables were the mood of the

parent (MMOOD), the level of cohesion within the family (COHES), and the reported behavior problems of the sibling (SBEHV). The first five measures were obtained from the siblings and the last three from the parents.

Additionally, the SEM included several exogenous variables as covariates. The ages of siblings (AGE) were believed to affect several study variables. The knowledge scores (SKNOW) of the siblings were controlled for age, treatment group placement (FULL and PART indicator variables), and three of the diagnoses (DXCYS, DXSPI, DXCAN as indicator variables). The reason for the use of these covariates is that the knowledge tests used in the study were not otherwise age or diagnosis standardized.

The reported income of the family at baseline (INCOME) and the highest grade of school completion of the respondent parent (GRADE) were used to construct a latent variable labeled SES in the path diagram. It was hypothesized that SES would be associated with two variables obtained by parent response: parental mood and the behavior problems of the sibling. The error terms of INCOME and GRADE were specified as correlated in the SEM.

The SEM used in the analysis, therefore, contained 17 variables, that is, the 16 measured variables and the latent SES variable, plus their associated error terms. The variables and hypothesized relationships among them are shown in Fig. 1, and the fitted model is shown in Fig. 2. For simplicity, Fig. 2 does not include error terms. To identify this model, it was assumed that the error terms had a standardized mean of 0 and a variance of 1.0.

The SEM is nonrecursive since a feedback loop exists among SSELF, SATT, and SMOOD. The procedure used to fit the model produced regression weights. All the hypothesized relationships in Fig. 2 were statistically significant (at least $p < 0.05$, two-tailed test). AMOS 4 was used to fit the structural equation models (Arbuckle, 1999).

A commonly used measure of model adequacy is the chi-square goodness-of-fit. However, this measure by itself is known to be a poor indicator of the usefulness or adequacy of some SEM, including nonrecursive ones such as that shown in Fig. 2. Both chi-square-related measures and other measures of model adequacy should be examined (Arbuckle, 1999). In this study, an additional chi-square-related measure was examined, namely the calculated chi-square goodness-of-fit divided by its degrees of freedom. Other goodness-of-fit indices (unadjusted and adjusted), however, were calculated and examined. Additionally, the minimum sample discrepancy, the root mean square error of approximation (RMSEA), and its level of significance (PCLOSE) were assessed. The comparative fit index, the incremental fit index (Dealta2 IFI), and the Hoelter values at 0.01 and 0.05 were calculated (Jaccard and Wan, 1996).

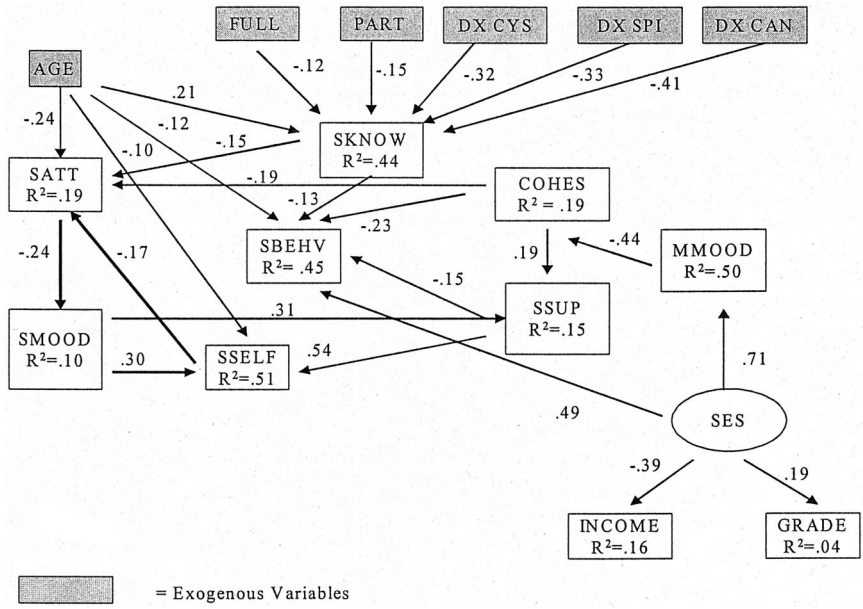

Fig. 2. Estimated Structural Equation Model (Baseline). (1) SKNOW = Sibling Knowledge About Illness, (2) SMOOD = Sibling Mood, (3) SATT = Sibling Attitude Towards Illness, (4) SSELF = Sibling Self-Esteem, (5) SSUP = Sibling Social Support, (6) SBEHV = Child Behavior Problem, (7) MMOOD = Parent Mood, (8) COHES = Family Cohesion, (9) AGE = The chronological age of the sibling reported at data collection, (10) FULL = Full treatment group, (11) PART = Partial treatment group, (12) DXCYS = Cystic fibrosis, (13) DXSPI = Spina bifida, (14) DXCAN = Cancer, (15) DXDIA = Diabetes, (16) DXDEV = Developmental disabilities, (17) SES = Socioeconomic Status, (18) INCOME = Annual family income, (19) GRADE = Education of the parent.

RESULTS

All measures of fit of the structural equation model suggest a good fit except the chi-square measure of 153.01, df = 93, $p = 0.001$. It is unlikely, however, that a very small chi-square goodness-of-fit measure can be obtained for a model with the many variables and parameters relative to the number of observations or study subjects, $N = 252$ (Jaccard and Wan, 1996). Other measures of fit, however, were excellent (Arbuckle, 1999).

A substantial improvement in fit occurred between a model assuming independence of the endogenous variables and the model shown in Fig. 1. The chi-square was reduced from 9119.68 in the independence model to 153.01, and the latter chi-square divided by its degrees of freedom was only 1.64. The fit indices, the CFI and Delta2 IFI, equaled 0.993. The RMSEA equaled 0.05 with a high and a low estimate of 0.036 and 0.065, respectively.

The PCLOSE was 0.451. The Hoelter criterion at 0.05 and 0.01 were around 200; actual numbers were 192 and 210, respectively. Also, substantial portions of the variances of most of the endogenous variables in the model were accounted for by the structural equations. The squared multiple correlation (r^2) of MMOOD was 0.50. The r^2 of the other study variables were SSELF (0.51), SBEHV (0.45), SKNOW (0.44.), COHES (0.19), SATT (0.19), SSUP (0.15), and SMOOD (0.10).

Standardized path coefficient or regression beta weights (b) are shown next to the arrows connecting the variables in Fig. 2. As noted earlier, all path coefficients were statistically significant at $p < 0.05$. All relationships in the model were in the hypothesized directions shown in Fig. 1.

Figure 2 shows the direct effects of the variables on each other. Among the more important findings are that SES strongly and directly affects both the behavior of the sibling (SBEHV, $b = 0.49$), and the mood of the parent (MMOOD, $b = 0.71$). The behavior of the sibling (SBEHV) is directly affected by SES as noted, but also by cohesion in the family (COHES, $b = -0.23$), age of the sibling (AGE, $b = -0.15$), support felt by the sibling (SSUP, $b = -0.15$), and knowledge about the illness of the sibling (SKNOW, $b = -0.13$). Thus, five variables directly affect the behavior of the sibling.

The knowledge of the sibling about illness (SKNOW) has a significant but modest direct effect on the attitude of the sibling toward the illness and its impact on the self and the family (SATT, $b = -0.12$). Sibling mood (SMOOD) directly affects sibling self-esteem (SSELF, $b = 0.30$), and self-esteem (SSELF) has a direct effect on the attitude of the sibling toward the illness (SATT, $b = -0.17$). Support felt by the sibling (SSUP) has a substantial direct effect on sibling self-esteem (SSELF, $b = 0.54$).

In this model of parent–sibling interaction, parent variables are related to each other and related both directly and indirectly to the behavior of the sibling. Mood of the parent (MMOOD) has a strong direct effect on cohesion within the family (COHES, $b = -0.44$). The mood of the parent (MMOOD), however, has no statistically significant direct effects on the behavior of the sibling (SBEHV) or the feeling of social support of the sibling (SSUP). Family cohesion (COHES), however, has direct effects on the behavior of the sibling (SBEHV, $b = -0.23$), the attitude of the sibling toward the illness (SATT, $b = -0.19$), and on the sibling's view of social support (SSUP, $b = 0.19$).

As previously noted, SES has strong direct effects on the mood of the parent (MMOOD) and the behavior of the sibling (SBEHV), but has no direct statistically significant impacts on other parent and sibling variables. The latent measure of SES in this model gives twice the weight to family income (INCOME, $b = -0.39$), as it does to the education of the parent (GRADE, $b = 0.19$).

Multiplying and summing all the direct and indirect effects following the paths in Fig. 2 provides measures of the total effects of each of the variables on another. Total effects include all the direct effects previously noted plus any indirect effects; that is, direct effects mediated or transmitted from one variable to another.

In this model, the total effects of SES are stronger than those of all other included variables on parental mood (MMOOD, $e = 0.708$), the behavior of the sibling (SBEHV, $e = 0.565$), and family cohesion (COHES, $e = -0.311$). These total effects and all others are in the hypothesized directions.

The knowledge about illness on the part of the sibling (SKNOW) is most strongly affected by the diagnoses of the ill brother or sister (the DXs or diagnostic categories in Fig. 2); however, this effect may be an artifact of test construction. Age of the sibling (AGE) has substantial effects on knowledge about illness (SKNOW, $e = 0.207$), with the older child generally having more knowledge.

After SES, the variable with the strongest total effect on the behavior of the sibling (SBEHV) is family cohesion (COHES, $e = -0.257$); however, all other variables but sibling self-esteem (SSELF) have modest or small statistically significant total effects on the behavior of the sibling. Mood of the sibling (SMOOD) is most strongly affected by the attitude of the sibling toward the illness (SATT, $e = -0.249$). Sibling self-esteem (SSELF) is strongly affected by sibling mood (SMOOD, $e = 0.472$) and feelings of social support (SSUP, $e = 0.552$); however, other variables also exhibit statistically significant total effects on sibling self-esteem, including family cohesion (COHES, $e = 0.127$).

Sibling feelings of social support (SSUP) are strongly affected by sibling mood (SMOOD, $e = 0.311$) and family cohesion (COHES, $e = 0.205$). Age of the sibling (AGE) has the strongest total effect on sibling attitudes toward the illness (SATT, $e = -0.257$), with the older sibling having a more positive attitude; however, cohesion within the family (COHES) has an effect on sibling attitude (SATT, $e = -0.216$) of almost similar size. Additionally, both sibling self-esteem (SSELF) and the knowledge of the sibling about illness (SKNOW) have important total effects on the attitude of the sibling toward the illness (SATT, $e = -0.178$ and $e = -0.125$, respectively).

DISCUSSION

All relationships in the fitted SEM were in the hypothesized directions and statistically significant (see Fig. 2). The interrelationships among the study variables found in the path analysis generally confirm theoretical expectations.

Both Harter (1983) and Williams *et al.* (1999) have identified what appear to be causal linkages among feelings of support, mood, and self-esteem among siblings of chronically ill children. In this study, these variables were linked statistically to each other and to the behavior problems of the sibling. The total effects of these variables on sibling behavior were modest compared to SES, the age of the sibling, and family cohesion. While SES and age cannot be changed by health-related interventions, family cohesion, sibling mood, feelings of support, and self-esteem may be alterable in directions producing positive changes in sibling behavior and health.

Indeed, a number of researchers have reported family cohesion and parental mood and behaviors to be strongly related to sibling mood and self-esteem. Sibling knowledge about the illness of the brother or sister has been shown to affect sibling attitude toward the illness and sibling mood (Graff, 2001).

These variables and relationships among them appear to be amenable to treatment through well-designed focused interventions. Learning and perception theory contains many insights into how knowledge and attitudes may be subject to cognitive and behavior modification (Prochaska and Velicer, 1997). Nurses, clinical psychologists, and other health professionals regularly apply learning and perception theories when intervening with patients. The findings of this study suggest that such interventions might be explored in family settings in which there is a chronic illness, or, at least, some attention should be given to the psychosocial variables mentioned earlier when health interventions are provided to these families.

The large effects of SES on both the behavior of the well sibling and the mood of the mother is consistent with findings reported in a growing literature on the effects of SES on health (Lynch and Kaplan, 2000). Also, the total effect of SES, which is mediated by mother's mood, on family cohesion is large. The SEM in Fig. 2 might be the first to demonstrate these SES effects quantitatively in families with chronically ill children.

This large SES effect suggests caution, at the least, concerning assertions about how much psychosocial variables may be modified to affect health outcomes within a given socioeconomic context. One may speculate that the implementation of learning and behavior modification based interventions may have much smaller or more limited observed effects within low SES families. Yet, these families may well be the ones that could benefit most from such interventions. Observations or evaluations of responses of low SES families to such interventions must explicitly consider these SES effects otherwise measured treatment effects are likely to be greatly underestimated.

The model also suggests that some negative SES effects might be mitigated by interventions enhancing family cohesion. While this may be

achievable, the task could be quite difficult in low-income households, particularly when one considers how much stress is placed on family cohesion by insufficient disposable income.

In the SEM results of this study, income has about twice the weight of the mother's education in the latent measure of SES. Programs outside "health" that provide adequate income support for or reduce fluctuations in family income are likely to be health enhancing. Large payoffs in health outcomes may arise from mitigating income reductions and pressures due to these. Such income support could be provided through income transfers or by services in-kind or at a subsidized price. Any laissez-faire policy that treats these families as if nothing has happened outside meeting the needs of the ill child is equivalent to disinvesting in the well-being of siblings, parents, and the family as a whole.

After fitting the model in Fig. 1, post hoc analyses were performed by adding paths to assess the possible effects of SES on family cohesion and the other variables in the model. Interestingly, none of these other variables exhibited a statistically significant direct association with SES when the other paths were retained. This result may suggest the crucial role that family cohesion has in transmitting both mothers' mood and SES to children in the family.

The SEM presented in this paper needs further testing and validation. Other researchers should do this with other groups of subjects. Clearly, a modest number of observations are used to estimate parameters of the model. An assessment of this or similar models using more low SES subjects and minorities could be helpful.

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