PREDICTING CAREGIVER STRESS:

AN ECOLOGICAL PERSPECTIVE

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Parenting necessarily entails a wide variety of experiences. It is often deeply satisfying and entertaining, and just as often it is frustrating and difficult. The great majority of parents could describe many experiences of both the satisfying and the frustrating type, including parents of children with severe emotional disturbances. Having a child with a serious illness or disability presents family caregivers with special challenges. When a child requires regular medical care, 24-hour supervision, and extensive behavior management, it is difficult to find the time to go grocery shopping and attend school functions or extra-curricular activities important to other children in the family; and it may be all but impossible to find the energy to work outside the home, care adequately for one's other children, or maintain an intimate relationship.

The reports of family caregivers regarding the ways in which their lives are affected by having a child with an emotional disturbance reflect the difficulties of caring for a child with special needs. In a large, national study of parents' perceptions of their needs and experiences with their children with emotional disabilities, more than half the caregivers surveyed said that their child's problems negatively affected family life in many areas (Friesen, 1989). Cross-sectional research has shown a relationship between children's emotional or behavioral problems and symptoms indicating parent or family distress. Such connections have been shown for family functioning in dysfunctional range (Bernstein, Svingen, & Garfinkel, 1990); a mothers' hostility toward spouses and fathers' aggressive response style (Johnson & OLeary, 1987); families' high irritability and overprotection (McFarlane, 1987); and mothers' and fathers' depression (Brown, Borden, Clingerman, & Jenkins, 1988; Kaslow, Rehm, Pollach, & Siegal, 1988). Despite the need for additional research to establish the direction of causality and to rule out spurious correlations, taken together these studies provide reason to presume a connection between children's emotional and behavioral problems and strain on parents and family. Nevertheless, families, including the families of children with severe emotional and behavioral problems, provide for many vital needs of their members, including socialization, affection, economic security, health care, recreation, and developing individual identity (Turnbull, Barber, Behr, & Kerns, 1988). Additionally, many family caregivers of children with severe emotional disturbances report that their lives are positively affected by their children (Friesen, 1989). This paper uses data from a large study of caregivers of children with serious emotional disorders to examine the family caregiving process from an ecological perspective.

Until very recently, the literature on families of children with emotional and behavioral disorders focused almost exclusively on the difficulties entailed in rearing children with disabilities and paid little or no attention to the life domains in which these families functioned well and to the positive contributions children with disabilities make to their families. Previous research also failed to differentiate the levels of family adaptation and functioning and the various factors which contribute to a family's relative well-being. For example, stress and coping among families with a child with a severe disability have tended to focus on the negative impact the child of concern has on the family, and only recently has research emphasized caregiver and family adaptation and coping strengths (cf., Cynic, Friedrich, & Greenberg, 1983; Turnbull et al., 1988).

Just as mounting concern for identifying and caring for children with emotional disturbances is a rather recent phenomenon (Knitzer, 1982), interest in ecological approaches to studying and working with families (Hartman & Laird, 1983), and the use of ecological and family systems models with families with children who have disabilities, in particular, are also relatively recent occurrences (Cynic, Friedrich, & Greenberg, 1983; Bubolz & Whiren, 1984). From an ecological perspective, it is insufficient to study families simply by examining effects of
parents on children and children on parents. A study of caregiver stress, for example, requires an examination of the various caregiver, child, family, and community factors that work together to affect the level of perceived caregiver stress. Understanding what caregivers and families experience as stressors, how they respond to stress, and why some thrive in spite of very high levels of stress is important in developing policy and designing interventions that will assist caregivers and families in caring for their children with disabilities.

The concepts, variables, and measures used in this study were based upon an extensive review of the literature. The dominate models of stress and coping were critically examined with concepts from several perspectives selected as potentially important to gaining an understanding of caregiving processes for families of children with emotional disorders. Given this ecological frame of reference, the family caregivers’ response to stress is based on two clusters of factors which influence coping, adaptation, and, ultimately, caregiver, child, and family outcomes. The first cluster consists of contextual factors, 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. The second cluster involves more dynamic factors seen as important to assisting families to care for difficult children such as formal social services, informal social support, and other resources available to family members. Ultimately the importance of all of these factors is their relationship to outcomes for caregivers including the positive and negative effects of these factors on caregiver health and well-being, child functioning, and family functioning.

While the family caregiver of a child with a severe emotional disturbance is arguably the single most important person in that child's life, the professional literature on family caregivers of children with emotional disorders is undeveloped (Friesen, 1989). This paper contributes to this literature by presenting the results of a study in which the family caregiving process is conceptualized from an ecological perspective and examined in light of outcomes for caregivers. Analyses are designed to determine the relative importance, individually and in combination, of various clusters of caregiver, child, family, and environmental characteristics and responses as predictors of caregiver stress.

**Methodology**

This study is based on data taken from a larger study of family caregivers of children with severe emotional disorders. Data were obtained from a survey of family caregivers who were identified with the help of the public mental health system in a state with a relatively welldeveloped mental health system response to families of children with serious emotional disorders. 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.

To ensure confidentiality families eligible for inclusion in the study were identified and initially contacted by state agencies. Once families agreed to be a part of the study they were contacted by the research team. Purposive sampling was used rather than representative sampling. This was because the goal of the study was to examine relationships between critical constructs identified in the ecological approach and a sample with adequate variation in the variables of interest was required for this purpose. There was no interest in obtaining a representative sample of the population which could be used to describe the characteristics of this population.

The first phase of the recruitment of families began with the identification of area mental health programs that provided diversity in service and population characteristics. The criteria
used to determine which area programs would be invited to participate were: (1) population diversity (primarily race and urban/rural); (2) community service diversity; (3) identification of children in the 3-5 age group; and (4) a willingness to participate. The second phase of selection of the sample was to establish contact and support from the regional child specialist in the four regions of the state who facilitated final agreements with agency administrators.

The family solicitation packet included: (1) a letter of support from the agency; (2) letter describing the project; and (3) a return card if they were willing to participate. Following the suggestions of Dillman (1978) on conducting mail surveys, the agency was asked to send out a reminder letter to all potential participants one week later. To insure 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. Ultimately, questionnaires were mailed to 335 families with 259 completing questionnaires.

Measures
The conceptual clusters making up the ecological perspective and the variables included in each are listed in Table 1. For each variable widely used measures were sought out and included. A brief description of each measure follows.

Child Characteristics. Measures of the child thought to be contributors to caregiver stress included the gender of the child, age (in years) and the child's problem behaviors and competencies (McDonald, Donner, and Poertner, 1992). The child's competencies were assessed by use of the Child Behavior Checklist/4-18 (Achenbach, 1991) which was designed to be filled out by parents and parent surrogates. For these analyses, the broad Total Competency Scale was used to assess the child's overall competencies. The CBCL competence items asks the caregiver to specify the child's involvement in sports, non-sports activities, organizations, jobs and chores, and friendships. Caregivers are also asked to indicated how much time the child spends in each activity and how well the child performs each one as compared to other children of the same age. In addition, competencies are assessed through the caregiver's rating of how well the child gets along with siblings, peers, and parents, and how well the child plays and works alone. Finally the caregiver rates the child's performance in academic subjects and is asked to indicate whether the child is in a special class or school, has repeated a grade, or has other school problems.

Behavioral and emotional problems are assessed on the CBCL through the use of a checklist of 118 problem items for which the caregiver is asked to assess the degree to which each item applies to their child. For these analyses the broad scales measuring internalizing behaviors (withdrawn, somatic and anxious/depressed) and externalizing problem behaviors (delinquent and aggressive) were used.

Achenbach (1991) reports that the inter-interviewer and test-retest reliability’s of the CBCL item scores were supported by intra-class correlations in the .90's and stability over a two year period. Inter-parent agreement was indicated by mean correlations ranging from .65 to .75. The instrument has been shown to be able to discriminate significantly between demographically matched referred and non-referred children and to be correlated with numerous analogous scales.

Family/Caregiver Characteristics. Characteristics of the family included in this analysis are: income (annual before taxes), number of other children living in the house, age of oldest child, and age of youngest child. Measures of the characteristics of the primary caregiver included:
marital status, race, education (years), employment status, age (years) and relationship to the child with an emotional disturbance.

Social and Formal Supports. Two widely used sub-scales of the Family Index of Regenerativity and Adaptation - General (FIRA-G) (McCubbin, 1987) were included in this study. The dimensions measured are "Relative and Friend Support" and "Social Support".

The scales for measuring the parent's experience with the formal support system were adapted from an instrument developed by the Portland Research and Training Center on Family Support and Children's Mental Health. The Professional Collaboration Scale consists of 12 items reflecting different aspects of a collaborative style of professional/client interaction (e.g., professional asked for your opinions, treats you as asset in child's treatment, sensitive to 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 services likely to be used by families with children with serious emotional disorders (e.g., special education classroom, social worker, psychologist, day treatment) and an additional category for specifying other service types. The scale score used here is simply the number of services ever used.

Coping Strategies. This study relied on the Coping Health Inventory for Parents (CHIP) developed by McCubbin et al. (1983) because it has been used extensively to measure coping patterns of families caring for a chronically ill member. The CHIP provides three sub-scales labeled: Integration, Cooperation, Optimism; Support, Esteem, Stability; and Medical Communication and Consultation.

Perception of Child. The current study measured perception by utilizing the Positive Contribution Scale (Behr, 1989) and the six items (Positive Outlook Scale) identified as measuring perception within the Coping Health Inventory for Parents (McCubbin & McCubbin, 1983). 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 caregiving to measure the parents perception regarding the positive contribution of their child to the parent's life and development. The scale consists of 53 items which can be grouped into nine sub-scales 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 life's purpose, pride and cooperation, personal growth and maturity, and career and job growth.

In the work describing the Family Caregiver Model (McDonald, Donner, and Poertner, 1992), it is argued that studies should differentiate between coping behaviors and cognitive coping. The latter is believed to be more usefully conceived as perception or appraisal. The CHIP includes six items which represent such cognitive processes (e.g., Believing in God, Believing that my child is getting the best care possible) which are described by McCubbin as "Optimism" and grouped with "Integration, Cooperation." For purposes of this study we use these six items as a separate "Positive Outlook" scale which is conceptually grouped with the other perception scales.

Caregiver Stress. The stress measure used was one 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 and 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 reports 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 reports a correlation of .63 between his scale and Hudson's Index of Clinical Stress (Press, n. d.).

Sample
Survey respondents were the primary caregivers for 259 children ages 4-12. Almost all of the children (94 percent) were living at home at the time of the survey. In nearly all cases (89 percent), 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 a small or large city (population of 25,000 or more), while one-quarter lived in small towns (population of 2,500 or less) or rural areas. While the majority of respondents reported their racial or ethnic identification as "White," almost one-third of respondents identified themselves as "Black." More than 20 percent of the respondents had not graduated from high school. Over 40 percent of the respondents were employed full-time while slightly more than half of the respondents' partners were employed fulltime. One-third of the respondents reported gross household annual income below $10,000.

Scores on the Achenbach Child Behavior Checklist (CBCL) indicate that the children represented in this study have severe emotional problems. Achenbach provided data for a normative sample of children as well as data for children referred for mental health services, making it possible to compare the children in this study to those samples. The average total problem score in this study was 76.0 for males and 65.0 for females, compared to Achenbach's normative sample scores of 24.3 for males (t = 28.84, df = 725, p < .001) and 23.1 for females (t = 17.94, df = 688, p < .001). The cohort referred for services in Achenbach's study had average scores of 54.5 for males (t = 8.49, df = 716, p < .01) and 52.1 for females (t = 3.49, df = 699, p < .01). Clearly the children identified by caregivers in this study are more disturbed than Achenbach's referred sample and suffer from severe emotional disorders.

Scores on Achenbach's Total Competence Scale were lower for children in this study than for Achenbach's normative sample. In this study, average Total Competence scores were 13.8 and 15.8 for males and females, respectively, compared to the normative sample scores of 18.6 for males and 18.7 for females. Each of these differences is statistically significant ( males: t=14.94, df= 602, p <.001; females: t = 5.65, df= 557, p < .001). Total competence scores for children in this study were not significantly different from Achenbach's sample referred for services, which had a mean score of 14.5 for males and 14.6 for females.

The caregivers in this study are confronted with a very stressful set of circumstances. The child of concern is severely disturbed, and most caregivers have at least one other child in the family. Many caregivers are single heads of families and the great majority are working, yet total household income is quite low and few of the caregivers reported receiving economic assistance. The stress experiences by these caregivers is confirmed by responses on the Press Stress Scale. Norms for the Press' scales are derived from a large study of 3,960 respondents who can be considered representative of the population and useful for making general comparisons. Press reports and average response of 3.3 for items on the Stress Scale and a difference of .2 required to indicate variance based on something other than measurement error (Press, 1993). Given Press' norms, caring for home and family was the most stressful life domain for the family caregivers in this study (mean = 4.06); followed by "your children" (mean = 3.97); and "your life in general" ( mean = 3.64). According to Press, "your life in general" is an item which offers a good indication of overall stress.
Analysis and Findings

From the ecological perspective this study sought to identify variables that best explained the stress reported by these caregivers. Due to the large number of independent variables considered here, the analysis proceeded hierarchically. First relationships of groups of variable with caregiver stress were examined to identify the most important predictor variables. This was done through both bivariate and multivariate analysis. Therefore, the first models tested were individual clusters of variables. Secondly the results of this model testing were used to build a multivariate equation with the best predictors from antecedent and mediator variables. Results are presented for the various independent variable clusters and finally for the overall model.

Child Characteristics. Five variables measuring characteristics of the child were analyzed in relation to caregiver stress: age, gender, internalizing problem behaviors, externalizing behaviors and total competency. Of these five variables only the problem behaviors were significantly related to caregiver stress. Increases in both internal and external problem behaviors were associated with higher levels of caregiver stress (r = .382 and .325 respectively, N = 257, p ≤ .001). These two measures were also the only ones to be statistically significant in a regression of caregiver stress on all five child measures (R2 = .254; F = 12.068; d.f. = 5, 177; p ≤ .0001).

Family/Caregiver Characteristics. Ten measures of characteristics of the family and primary caregiver were examined (relationship to the child, marital status, race, age, education, employment, family income, number of other children, age of youngest child and age of oldest child). Three bivariate relationships were significant. Caregivers who were employed full or part time had higher stress levels than those who were not employed (t = 1.97, d.f. = 255, p = .05) and mothers reported higher stress levels than did fathers or other caregivers (t = 2.45, d.f. = 256, p = .015). Whites reported significantly higher stress levels than non-white (t = 3.54, d.f. = 257, p ≤ .001). Race was the only variable to remain significant in the multiple regression of caregiver stress on all ten family and caregiver characteristics (R2 = .067; F = 2.10; d.f. = 10, 229; p = .025).

Social and Formal Support. The "Relative and Friend Support" scale was not related to caregiver stress in either the bivariate or multivariate analyses. The "Social Support" scale was negatively correlated (r = -.216, n = 249, p ≤ .001). This indicates that greater social support was associated with lower levels of caregiver stress.

While no relationship was found between caregiver stress and services currently used, a linear relationship was found to exist between stress and the number of services ever used. Given the complex inter-relationships between services, problems and stress over time, the positive correlation between service use and stress is more likely to indicate that service use was in response to stress, that is, higher stress leads to more use of services.

The professional collaboration scale was not found to be related to caregiver stress in either the bivariate analyses or in the multiple regression. Therefore, of all the measures of formal and social support, only the Social Support scale was a significant predictor of stress in the expected direction.

Coping. None of the three original coping sub-scales from the Coping Health Inventory for Parents were significantly related to caregiver stress. However, in the multiple regression of
stress on the three coping scales, two of the scales were found to be significant. Greater use of "Medial Communication and Consultation" was associated with higher stress scores while higher scores on "Integration, Cooperation and Optimism" were associated with lower stress levels. The overall regression of caregiver stress on the three coping scales was statistically significant ( R^2 = .034; F = 2.96; d.f. = 3, 254; p = .033).

**Perception.** Two of the nine scales measuring caregiver perception of the positive contribution of the child were significantly correlated with caregiver stress. Higher scores on the "Perception of the Child as a Source of Pride and Family Cooperation" sub-scale were associated with lower caregiver stress (r = -.132, n = 258, p = .034). However, higher scores on the "Perception of the Child as a Source of Awareness about Future Issues" subscale were associated with higher caregiver stress (r = .139, n = 254, p = .026). Both of these variables remained significant and in the opposite direction in a regression of caregiver stress on all nine perception scales (R^2 = .084; F = 2.43; d.f. = 9, 237; p = .012).

The "Positive Outlook" sub-scale reflecting perceptions (cognitive coping) was significantly correlated with stress (r= -.147, N = 258, p = .018). Higher user of these perceptual responses was associated with lower caregiver stress. When combined in a multiple regression with the two perception of positive contribution scales, all three variables continued to be statistically significant (R^2 = .086; F = 7.79; d.f. = 3, 249; p = .0001). Prediction of Caregiver Stress

All antecedents found to be significantly related to caregiver stress in either the bivariate or multiple regression analyses described above were next included in a single regression equation. Results from this analysis are shown in Table 2. Overall the equation combining variables is highly significant explaining over 30 percent of the variance in caregiver stress. The strongest single predictor is the internalizing behaviors of the children (more internalizing behaviors predicts higher stress). Other highly significant variables (p ≤ .01) are relationship to child, awareness of future issues, and race. Mothers, caregivers who perceive their child as enhancing their awareness of future issues and Whites report higher stress levels.

Externalized problem behaviors and being employed are significant between the .01 and .05 levels of significance. Social support becomes marginally significant and the "Use of Medical Communication and Consultation" as a coping mechanism and the perception scales of "Pride and Cooperation" and "Maintaining a Positive Outlook" are no longer significant.

**Implications and Conclusions**

Since this is one of the first large scale studies of stress and coping of caregivers of children with serious emotional disorders, it adds to the growing literature on this important topic. Clearly more studies are needed to further explicate important relationships between difficult behaviors of children, the stress experienced by their caregivers, and those mechanisms or assists that help caregivers continue to provide care and maintain their own health. In many ways this study is exploratory and this field will benefit greatly from improved theories, measures, and methodologically more sophisticated research.

Despite these cautions, the findings of this study contain important implications for research, policy, and practice. The significance of the child's problem behaviors, particularly internal behaviors, in contributing to caregiver stress is important since it is typically the external problems that draw public and professional attention to a child. The child who fights or destroys things for no apparent reason is frequently seen as a problem before the child who may be quiet and withdrawn. While both of these problem types contribute to caregiver stress, it is the internal
problems that caregivers report to be most stressful. Interestingly, child's gender and age are not predictors of caregiver stress in this study. This is an unexpected finding since practice wisdom and research with other populations suggests that older children are more difficult to care for as are boys. Practitioners working with parents of children with serious emotional disorders need to keep these results in mind and explore with parents the effects of the both internal and external problem behaviors on the caregiver. Any tendency on the part of practitioners to de-emphasize the importance of problem behaviors of young children or females ought to be resisted. This study together with the reports of many parents suggest that these behaviors exhibited by both genders and at all ages are very difficult to manage.

While there is a growing body of literature suggesting that a strengths approach to working with these children and families is useful (Friesen & Poertner, 1995), several findings from this study raise important issues for this approach. One might expect that a child's competence would alleviate the stressful effects of the child's problem behaviors. However, a child's competence was not found to be related to caregiver stress. There are several alternative explanations for this finding including measurement problems, the severity of the children's problem behaviors, and relying on a single (caregiver's) perspective.

If the child's strengths or competencies are to influence caregiver stress, the caregiver must first be able to recognize these strengths. Practice wisdom suggests that for many parents the child's problem behaviors are so difficult to manage that it is very hard for them to recognize positive or competent behaviors in their children. The findings presented here that the caregiver's ability to maintain a positive outlook and to perceive the child as a source of pride and family cooperation are associated with lower stress suggests that strengths, when recognized by the caregiver, can influence outcomes. Other research supports this finding and indicates that caregivers want practitioners to give them hope (Turnbull, et. al. 1988 and 1989; Donner, et. al. 1995). However, findings from our study also suggest that not all positive perceptions of the child result in positive outcomes. Higher scores on the perception of the child as a source of awareness about future issues were associated with higher caregiver stress. Perhaps the enhanced awareness, in the absence of the perceived ability to act in a meaningful way on this awareness, leads to greater worry and frustration. It is not surprising that a caregiver who considers what it is going to be like for the child when he/she reaches another level in school or exits school and tries to make it in the community will experience this as stressful. These children are not well understood and few services or programs exist to help them function in the community. While it is not useful for practitioners to be overly simplistic in terms of giving caregivers reason to hope, this dimension of practice is important and may best be done by linking caregivers to others in similar situations. Parent groups with caregivers who have children at various ages and stages of development may be the best way for caregivers to address the future in a way that does not increase stress. Clearly, perception is a complicated process which must be explored carefully if beneficial intervention strategies are to emerge.

The findings that relationship to the child, employment, and race are significantly related to caregiver stress have additional implications for practice and research. While this study was not designed to identify cultural differences, they exist. Studies need to be conducted that focus on cultural differences in caregiving of children with emotional disorders. Until this area is more completely developed it is important for practitioners to explore with caregivers the significance of cultural background to their caregiving. As has been pointed out in other fields, ignoring race may be as problematic as using racial stereotypes (Bryant, 1995). Exploring an individuals meaning of the cultural context is indicated by this study.
Clearly caring for children is still predominately defined as a maternal task which helps explain why the relationship to the child was an important predictor of stress. Couple this with the need for so many maternal caregivers to work at the same time they are trying to manage very difficult behavior and it is not surprising that employment is an important predictor of stress. This provides practitioners with important areas to address. Anything that would help the maternal caregiver with the care of the child and enhance the economic resources within the household could alleviate stress. This could range from helping the mother obtain suitable caregiving assistance within the home, to appropriate day care, to economic assistance.

The findings of this study that social and formal supports as well as various coping strategies do not predict caregiver stress is problematic for the children's mental health field. While there may well be measurement problems here, particularly with formal services, the field places a great deal of emphasis on the usefulness of social support and professional collaboration as well as formal services. Children's mental health programs attempt to assist caregivers through collaboration, brokering formal service, and enhancing social supports. Research needs to determine what it is that would assist caregivers to reduce the stress of caring for a child with a serious emotional disorder. Similarly this study suggests that we know very little about how these caregivers cope with caring for a child who exhibits very difficult behaviors. This remains an important area for conceptual as well as empirical work.
Table 1

Predictor Variable Clusters

Child Characteristics

- age
- gender
- internalizing problems*
- externalizing problems*
- total competence

Family/Caregiver Characteristics

- caregiver
- relation to child*
- marital status race*
- age
- education
- employment*
- family income
- number of other children
- age of youngest child
- age of oldest child

Social and Formal Support

- Relative and friend support
- Social support index*
- Services
- Professional collaboration

Coping

- Integration, Cooperation, Optimism*
- Support, Esteem, Stability
- Medical Communication and Consultation*

Perception of Child

- Child is a source of happiness and fulfillment
- Child is a source of expanded social network
- Child is a source of strength and family closeness
- Child is a source of awareness of future issues*
- Child is a source of learning
- Child is a source of understanding life’s purpose
- Child is a source of pride and cooperation*
- Child is a source of personal growth and maturity
- Child is a source of career and job growth
- Positive outlook*

* Significantly related to caregiver stress in either correlation or regression within cluster analyses.
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<th>std. error B</th>
<th>Beta</th>
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Multiple R  .54360  
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Adjusted R Square  .26487  
Standard Error  10.44962  
F = 9.64724; df = 10, 230  Signif F = .0000
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