# The Importance of Family Functioning to Caregiver Adaptation in Mothers of Child Cancer Patients: Testing a Social Ecological Model

Johanna Shapiro, PhD, Myriam Perez, MSIV, and M. James Warden, MD

This study was designed to investigate associations between family relationships, personal-psychological caregiver adaptation (ie, depressive symptomatology, sense of burden), and ability to function within the health care system (perceived doctor-parent relationship) in mothers of child cancer patients. Data were collected through a survey of a sample of 29 mothers whose children were diagnosed with some form of childhood cancer, mainly leukemia. Family functioning was positively related to both caregiver adaptation and doctor-parent relationship. Mothers who reported decreased maternal depression and burden were significantly more likely to report respectively improved spousal relationships and improved spousal communication. Mothers reporting more positive doctor-parent relationships also described themselves as having improved relationships with spouse and child, and improved spousal communication. Maternal well-being and doctor-parent relationship were not directly related. By suggesting that both intrapsychic and instrumental maternal adaptation are influenced by positive relationships in the family, this study provides support for the social ecological model of stress. The possibility that family factors exert a direct influence on both caregiver intrapsychic well-being and instrumental skills argues for the importance of their being carefully considered in any models evaluating caregiver adaptation.

THE PRIMARY CAREGIVER, usually the mother, is a key link in the quality of care received by the pediatric oncology patient.[1] Physicians and other health care personnel rely on this individual (or group of individuals) to provide daily care and transportation, administer medications, supply emotional support, and serve as the informational conduit to other family members.[2] The well-being of caregivers is important in and of itself because of direct and indirect costs associated with increased illness in this population.[3] However, caregiver well-being is also important as a means to the end of delivering competent care to the child. Both of these issues are well-documented among caregivers of the elderly[4,5] but have received less attention when the identified patient is a child.

Many models have been developed to explain the effect of a stressor such as life-threatening illness on the individual and family.[6-9] Bronfenbrenner's[10] social ecological model studies the relationship of human beings to the settings and contexts in which

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*From the Departments of Family Medicine and Surgery, University of California, Irvine, CA.*

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*Address reprint requests to Johanna Shapiro, PhD, Department of Family Medicine, UCI Medical Center, Bldg 200, Rt 81, 101 The City Drive South, Orange, CA 92868-3298.*

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they are actively involved. His theory posits four levels of "nested concentric structures," all of which exert influences of varying degrees on the individual. These consist of microsystems, mesosystems, exosystems, and macrosystems. Microsystems are the immediate systems with which the individual interacts, such as the family, the workplace, or the school. Mesosystems are interrelated microsystems, eg, the "system" created by the interaction of family and school. Exosystems are systems that tend to exert indirect, rather than direct, effects on the individual, such as the neighborhood, media, and government agencies. Macrosystems pertain to the ideological patterns of the culture and relevant subculture that influence the individual. In Bronfenbrenner's model, interactions are multidirectional, so that systems influence each other, as well as the individual, and the individual also exerts influence on the various systems in which he/she participates.

One implication of social ecological theory is that each ecological system is in turn influenced by the larger systems within which it must operate and with which it must interact. This hierarchy of influence associated with the differing levels of ecological contexts suggests the possibility that individuals might be most affected by the social-ecological niche with which they share greatest proximity.[11]

Applications of social ecological theory to chronic childhood disease and disability have been made by Crnic et al,[8] Kazak,[12] and Kazak and Nachman,[2] among others. Crnic, discussing the families of children with developmental disabilities, makes the point that individual coping resources are mediated by the various ecological domains with which the individual interacts. Nihira, using a similar population of families with moderately to severely retarded children, identified the mesosystem of interrelationship between family and school systems, and concluded that family coping in the home environment influences child adaptation in the school environment.[13] Kazak and Nachman identified the family as the microsystem most important in influencing psychosocial adaptation among child oncology patients, but also stressed the influence of mesosystems such as the family's social support network and family interaction with the health care system.

Although Bronfenbrenner's model was originally intended to shed light on developmental issues in children, it can also be applied to adults.[8] For example, in seeking to understand the complex process of parental adjustment to childhood cancer, we can view parents as individuals at the center of a series of concentric rings that affect the individual and that the individual in turn influences. To begin to test this model, we need to decide which elements should be focused on, and how they should be operationalized.

One measure of individual adaptation is level of psychological distress, and this appears particularly relevant in families of child cancer patients. In situations of chronic and/or life-threatening pediatric illness, parents are at risk for psychological distress, including depression.[14,15] In terms of pediatric cancer, empirical research with mothers of children with cancer has shown increased levels of depression compared to mothers of children with non–life-threatening illness.[16]

In addition to depression, sense of burden is another significant contributor to parental psychological distress.[17] Burden is defined as a perceived lack of support and shared caregiving duties between parents and the absence of an adequate support system. Burden, as perceived by both parents and nurses, has been noted to increase to statistically significant levels in families caring for children with cancer compared to other chronic, non–life-threatening illnesses.[18]

Existing literature suggests that a key microsystem in adaptation to childhood cancer is the family unit. The impact of the child with cancer on the family, and how the family responds to this stressor are critical predictors of the individual functioning of family members. Pediatric cancer has a profound psychosocial impact on the entire family unit.[19,20] Families of children with cancer are forced to adapt to changes in both spousal and parent-child relationships. Both negative and positive changes in the relationship between parents have been cited in the literature. One study concluded that the presence of chronic unresolved conflict between parents about perceptions of the meaning, seriousness, and treatment of their child's illness was a strong negative influence on parental well-being.[21] Another study of 20 families of child cancer patients found the marital dyads to be significantly less well-adjusted than married norms (although significantly more adjusted than a divorced sample).[22]

However, changes in the parents' relationship are not always negative. In fact, some literature indicates that, retrospectively, a majority of couples interviewed report that the cancer experience brought them closer.[23] An older study also found that 96% of parents of child cancer patients reported either improved or unchanged feelings toward their spouse since their child's diagnosis.[24] A more recent study[25] noted that 56% of 98 parents of child cancer patients reported no change in their relationship with their spouse, 29% described a more positive relationship, and 15% had a less positive relationship. In this same study, a less positive relationship with one's spouse and marital tension were both significantly associated with higher emotional distress (malaise). In other studies, supportive communication with the spouse was shown to influence the mother's well-being and sense of burden,[21] as well as overall adjustment.[26]

The relationship between the parental caregiver and sick child also has been noted to change during the course of treatment. Initially, the relationship may be overprotective on the parent's part and regressive on the part of the child. Later problems may arise between the child and the primary caretaker, including child discipline problems, acting-out behaviors, and self-defeating or injurious acts. However, research also notes parental reports of increased intimacy and openness with affected children.[23,27]

Another microsystem that will exert a profound influence on the adaptation of parents of children with cancer is the health care system. In the interactions between the family members (usually parents) and health care professionals, we see the opportunity to identify a mesosystem in Bronfenbrenner's terms that should exert an influence both on the microsystem of the family and on individual adaptation. Indeed, the ability to establish a good doctor-parent relationship is a major component of how well parents adapt to their critically important role of caregiver. For example, the family's relationships with physician and staff influence how openly parents are able to communicate regarding their child's condition, and ultimately affect their medically related decisions.[28] In a recent survey, caregivers rated their desire for mutually considerate and respectful interactions with the medical staff and their desire for information about the disease, treatment, and prognosis of the patient as their greatest needs.[29] Recognition of the importance of communication between parents and physicians has given rise to a variety of methodologies, including the use of taped interviews that may be reviewed and shared with others as needed by parents.[30] One study specific to pediatric cancer indicates that parents' relationships to their child's health care providers are positively associated with parental assumption of responsibility for compliance with their child's treatment regimen.[31] In a review article, Kupst[26] concludes that forming an alliance with the oncology team is an essential element in adaptive family coping.

For the purposes of this study, individual parental adaptation was measured through variables of depression and burden; the family microsystem was assessed through positive or negative changes in family relationships and spousal communication that were attributed to the child's cancer diagnosis; and the mesosystem of family-health care system interaction was measured through the variable of doctor-parent relationship.

The study asked the following research question: What are the relationships between individual adaptation, the microsystem of the family, and the mesosystem of the doctor-parent relationship? We hypothesized that positive changes in the family microsystem would be associated "downward" with decreased individual depression and burden; and "upward" with more positive doctor-parent relationships in the mesosystem created by family-health care system interactions. Following the lead of Bailey et al[11] regarding the relative importance of the proximity of the nested spheres of influence, we predicted that there would be no direct relationship between mesosystem and individual adaptation variables.

## Method

The study was conducted during the seventh annual University of California, Irvine pediatric oncology family weekend retreat. This event brings together faculty, health professionals, and pediatric oncology patients and their families to discuss therapies and research protocols, in addition to providing support and exploring psychosocial issues concerning the patient and family unit. Participation in this study was voluntary. Of the fifty-five families in attendance, 29 families responded (52.7%). The mother from each of these families, self-identified as the primary caregiver, responded to a brief questionnaire.

Respondents' mean age was 38.7 years. The majority were married, with only one divorced and one single mother in the sample. The group consisted of 20 white, 6 Latino, and 1 Asian families (two mothers did not specify their ethnicity). Sixteen of these primary caregivers worked full time, three held part-time positions, and 10 did not work. The sick children ranged in age from 2 to 16 years, with a mean age of 9.2 years. Time since diagnosis ranged from 2 months to 7 years; the mean was 33.8 months. Twenty-two of the children were diagnosed with some form of leukemia, and the remaining seven had a type of solid tumor. At the time of the study, 20 of the children were in remission, and five youngsters had relapsed within the past 2 years, while four were in treatment and had not experienced a remission (Table 1).

TABLE 1.
Demographic Characteristics of Sample

| Characteristic | Percentage |
|---|---|
| Mothers (age range, 29-47 years; mean age = 38.7 years) | |
| Married | 93.1 |
| Some college | 86.2 |
| Working | 69.0 |
| Religious | 72.4 |
| Annual income >$35,000 | 85.7 |
| Non-Hispanic white | 74.1 |
| Latino | 22.2 |
| Children (age range, 2-16 years; mean age = 9.2 years) | |
| Boys | 58.6 |
| Remission | 69.0 |
| Relapse | 17.2 |

## Instruments

Using a 60-item questionnaire that took approximately 15 minutes to complete, respondents rated their level of depression and sense of burden, and also responded to questions about changes in family relationships and communication patterns since their child's diagnosis, as well as to questions regarding the nature of their relationship with their child's primary physician.

Depression levels were assessed using the CES-D scale[32] (sample range, 7-41, of a possible 0-60). The CES-D is a 20-item self-reporting rating scale that has been used for 20 years to elicit symptoms of depression in community samples. Items were selected for inclusion from previously validated depression scales to represent the major components of depression, including depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, and loss of appetite and sleep disturbance. The reliability and validity of the scale have been tested on a variety of clinic and community samples and indicate the scale has good internal consistency, acceptable test-retest stability, good concurrent validity, and evidence of construct validity.[33] In this study, the CES-D had an internal alpha reliability of .90.

Burden was assessed through the statistical development of a scale (sample range, 4-13 of a possible 0-20) consisting of four items rated on a 5 point Likert-type scale, such as, "I do not feel that the burden of caregiving is shared in our family" and "I can talk to my spouse about my child's health status." The Cronbach's alpha for internal reliability achieved for this scale was .63. Statements were patterned on selected items from the Caregiver Burden Scale,[34] developed for use with caregivers of elderly patients.

Relational changes in the family were assessed through two single-item questions offering three response options (eg, "Since your child's diagnosis, has your relationship with your spouse/child *improved, gotten worse,* or *stayed the same?*"). Changes in communication with the spouse were similarly measured through a single-item offering three levels of response.

Doctor-parent relationship was also assessed through the statistical construction of a scale consisting of seven items rated on a 5-point, Likert-type scale, (sample range, 16-28 of a possible 0-35), including items such as "I feel my doctor treats me with respect," and "The doctor does not take the time to make sure I understand information about my child." The Cronbach's alpha achieved for this scale was .78.

## Data Analysis

Because of the small number of respondents who indicated a worsening in their spousal relationships or communication, responses to this variable were dichotomized into "improved" and "stayed the same or got worse." Data were analyzed using correlations for continuous variables (intercorrelations of the three scales: depression, burden, and doctor-parent relations); both two-tail *t*-tests and the Mann-Whitney U Test were used for comparisons of the dichotomous variable (change in spousal/child relationships; changes in spousal communication) with continuous variables. Because of the small sample size, the more stringent nonparametric z score of the Mann-Whitney U test was used to determine significance level. Power analysis indicated a 95% chance of detecting a moderate to large effect in group comparisons.[35]

## Results

The results of the depression measure, using the CES-D screening scale cut-off score of 16, showed our sample to have a mean score of 24.2 (SD = 9.9). Mothers who reported positive changes in their relationships with spouses were significantly more likely to report less depressive symptomatology. Similarly, positive communication changes between subjects and spouses was significantly associated with decreased sense of burden. Subjects reporting improved spousal relationships, improved communication with spouse, and improved relationships with their child were also significantly more likely to have good doctor-parent relationships. There were no relationships between depression, burden, and doctor-parent relationship. No demographic variables of either mother or child, including child age, duration of illness, and remission status, were related to any of the study variables of interest (for a summary of results, see Table 2).

## Discussion

As hypothesized, caregivers' depressive symptomatology and sense of burden were directly and negatively related to perceived improvements respectively in relations or communications with their spouses, while a better doctor-parent relationship was also related to improvements in family functioning. These findings are summarized in Figure 1. One possible interpretation is that aspects of family functioning are mediary between the personal psychological level of adaptation and the instrumental level of adaptation, required by the mesosystem of interaction with the larger health care system. This finding suggests the importance of family variables in influencing different levels of caregiver functioning.

The majority of respondents in this study reported improved family relations, a finding that replicates previous reports regarding this issue.[26] However, the group mean depression score of 24.2 indicates a sample with significantly more depressive symptoms than a normative sample ($\bar{x} = 8.0$; $P < .05$) and not significantly different than a sample of psychiatric patients ($\bar{x} = 24.1$; NS).[33] This finding, as well as evidence of moderate levels of burden, suggests that although positive change in spousal relationships may be related to decreased depressive symptoms, such changes cannot fully attenuate the ini-

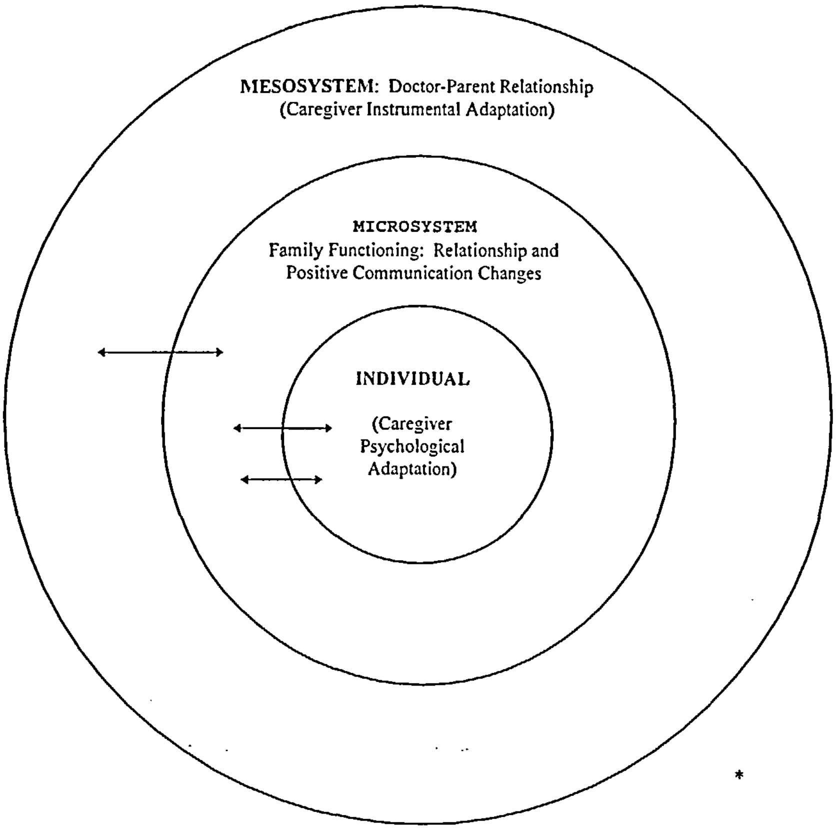

FIGURE 1. Social ecological model of relationships between family function and caregiver adaptation variables. Ecosystem and macrosystem variables were not investigated in this study.

TABLE 2.
Relationships Between Dimensions of Caregiver Adaptation and Family Functioning

| | Child Relation | | Spouse Relation | | Spouse Communication | |
|---|---|---|---|---|---|---|
| Caregiver Adaptation | Improved | Not Improved | Improved | Not Improved | Improved | Not Improved |
| Depression | | | | | | |
| x | 24.7 | 19.7 | 18.8 | 27.6 | 24.3 | 29.3 |
| SD | 9.2 | 10.0 | 7.6 | 9.6 | 9.8 | 9.4 |
| z | −1.2 | | −2.15 | | −1.02 | |
| *P* | n.s. | | .03 | | n.s. | |
| Burden | | | | | | |
| x | 6.8 | 7.7 | 7.2 | 7.1 | 6.1 | 8.5 |
| SD | 2.4 | 3.3 | 2.5 | 3.4 | 2.7 | 2.5 |
| z | −.48 | | −.30 | | −2.1 | |
| *P* | n.s. | | n.s. | | .03 | |
| Doctor-Parent Relationship | | | | | | |
| x | 24.9 | 21.4 | 25.4 | 21.0 | 25.6 | 21.9 |
| SD | 3.1 | 3.5 | 2.5 | 3.2 | 1.8 | 3.8 |
| z | 2.09 | | 2.8 | | −2.1 | |
| *P* | .04 | | .006 | | .04 | |

tial psychological impact of a pediatric cancer diagnosis.

The conclusions of this study are limited in several respects. The wide spectrum of child ages represented in the sample may have confounded family developmental and life-cycle issues with the variables under investigation. Variability in the time since diagnosis meant that we were forced to include both recent and distant retrospective recall of perceptions in the same sample. On the other hand, analyses of the sample by child age, diagnosis, length of time since diagnosis, and remission status revealed no significant differences among parents on any of the variables of interest.

With regard to the nonrandom sample of convenience, parents who attended the oncology retreat may be considered more active than other caregivers of pediatric cancer patients in terms of seeking information, help, and support. Further, the relatively low response rate may have introduced further bias although, as noted previously, anecdotal reports from staff did not identify any systematic differences between responders and nonresponders. Finally, the small size of the sample precluded the use of predictive statistics such as multiple regression in our analytic strategies. Thus, definitive resolution of questions of causal relationships in the data can be achieved only through a larger, more representative study.

Placing our data in the context of the social ecological model suggests that family relationships may be a key link between individual and systemic levels of functioning. Thus, a positive family environment may exert a beneficial effect downward on individual parental psychosocial adaptation, and a beneficial influence upward on the larger system of the doctor-parent relationship. The possibility of the primacy of family factors in the equation of adaptation to childhood cancer deserves further, more systematic exploration.

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