Associations of Paternal Involvement in Disease Management with Maternal and Family Outcomes in Families with Children with Chronic Illness

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Objective  The role of fathers in pediatric disease management and its associations with family functioning have rarely been the focus of empirical study. In this study, we used the Dads Active Disease Support scale (DADS), a measure of the amount and helpfulness of paternal involvement in pediatric disease management, to explore the association between father involvement and other aspects of family functioning.  Method  A sample of 190 heterosexual couples completed the DADS and measures of maternal, marital, and family functioning.  Results  Maternal report of higher ratings on DADS Helpfulness scale was associated with fewer self-reported maternal psychiatric symptoms and less perceived impact of the disease on family functioning. Both mothers’ and fathers’ reports indicated that more paternal involvement was related to more favorable outcomes in marital satisfaction and family functioning.  Conclusions  More paternal involvement in disease management was associated with healthier maternal, marital, and family functioning. Longitudinal studies are needed to determine whether paternal involvement is likely to be a fruitful target for psychological intervention.

Key words  adjustment; chronic illness; family; fathers; mothers; support.

Childhood chronic illness imposes significant stress on the family. Performing daily medical tasks, dispensing medications, refilling prescriptions, managing insurance, attending doctor’s office visits, obtaining laboratory tests, and hospitalizations are only a few of the activities families must take on. The burden of these tasks can place stress on the parents, marriage, and family (Klinnert, Gavin, Wamboldt, & Mrazek, 1992; Wallander, Varni, Babani, & Wilcox, 1989).

Many studies have found that simply having a child with a handicap or chronic illness is not related to poor parental and family adjustment (Spaulding & Morgan, 1986; Wallander, Varni, Babani, DeHaan, et al., 1989). In fact, there appears to be wide variation in how mothers and families adjust to having a child with special needs.

There is evidence that aspects of the social environment may determine family adaptation to child chronic illness. Research highlights the importance of social support in buffering the effects of chronic stress (Cohen, Underwood, & Gottlieb, 2000). Within the realm of child illness, studies have suggested that parents with greater social support show fewer psychological symptoms than those with less social support (Kazak et al., 1997). In a study of developmentally disabled young children, Bristol, Gallagher, and Schopler (1988) demonstrated that perceived spousal support was related to parental adaptation. The degree to which family members provide one another with emotional and instrumental support may be one key to successful adaptation.

Mothers assume most of the burden of child illness management (Bristol et al., 1988; Cook, 1984; Quittner, DiGirolamo, Michel, & Eigen 1992). Thus, many of the studies examining family adaptation to child illness or handicap have focused on maternal functioning as mothers are presumed to be at greatest risk for distress. Wallander, Varni, Babani, DeHaan, et al. (1989) found...
that features of the social environment such as family support, marital satisfaction, and social support network were more important to maternal social–emotional functioning than disability status of the child. In a study of parents of children with cancer, Barbarin, Hughes, and Chesler (1985) found that for wives, marital quality was associated with the husband’s involvement in the care of the sick child. Quittner et al. (1992) found that among parents of children recently diagnosed with cystic fibrosis (CF), maternal adjustment (specifically depression) was related to role strain. Role strain in this study was defined as strain in managing the caregiving role, and part of this construct included the degree to which the spouse was present, was helpful, and assisted with medical routines.

Wallander, Varni, Babani, Banis, et al. (1989) proposed a Risk and Resistance Model of maternal and family adaptation to pediatric chronic illnesses or handicapping conditions. Their model proposes that manifestation of the adverse effects of certain Risk Factors (e.g., parameters of the disease/disability, functional independence, and psychosocial stressors) on Adaptation (e.g., mental, physical, and social functioning) may be attenuated by a variety of Resistance Factors (e.g., intrapersonal, social–ecological, and stress processing variables). Among the social–ecological factors mentioned by the authors were family environment, social support, family members’ adaptation, and utilitarian resources. The current study can be viewed in the context of the Wallander, Varni, Babani, Banis, et al. (1989) Risk and Resistance Model as an examination of the contributions of several specific social–ecological resistance factors. According to this model, the amount and helpfulness of paternal involvement in pediatric chronic disease management is likely to influence maternal adaptation to this set of stressors. This study was designed to determine whether more paternal involvement was associated with more favorable adaptation to pediatric chronic diseases as measured by indices of maternal psychological adjustment, marital satisfaction, and family functioning.

In this study, we used a newly developed measure of fathers’ illness-related support (Wysocki & Gavin, 2004) to explore associations between father’s involvement and measures of maternal, marital, and family functioning. Based on the social support literature (Cohen et al., 2000) and the Wallander et al. model in particular, we hypothesized that these outcomes would be more favorable in families where mothers and fathers rated fathers as doing more tasks and being more helpful than in those families where fathers did less and were perceived as less helpful. Specifically, we predicted that maternal ratings of father involvement would be positively related to mothers’ ratings of maternal adjustment, family adjustment, and marital adjustment, and negatively related to parenting stress. In turn, we predicted that paternal ratings of father involvement would also be positively related to mothers’ ratings of maternal adjustment, family adjustment, and marital adjustment, and negatively related to parenting stress.

Method

Research Design and Participants

We utilized a cross-sectional, correlational design wherein data collection occurred at a single point in time for each family. Participants were adult heterosexual couples who were the caregivers of, and living with, a child between the ages of 2 and 18 years diagnosed with one of six chronic medical conditions: asthma (at least mild persistent in severity), cystic fibrosis, type 1 diabetes mellitus, phenylketonuria (PKU), inflammatory bowel disease, or spina bifida. These conditions were selected for study because all are managed with complex medical regimens, require regular monitoring, medication, or dietary intervention, are relatively common in the pediatric age group, and because empirical data and clinical observations indicate that effective family adaptation is critical to successful management of these conditions.

Participants included biological parents, stepparents, and couples who lived together for at least 6 months but were not married. Only those adult caregivers living with the identified patient were enrolled. Inclusion criteria required that each child was in treatment with a regimen requiring daily administration of prescribed medication(s) or dietary products, regular clinic appointments, and symptom monitoring. The patient’s physician must have expected the patient to be on this regimen for at least 6 months.

Beginning with a sample of 374 potentially eligible families, 224 couples (mothers or other female caregivers and fathers or other male caregivers) participated in the study. Of the 224 couples who agreed to participate and contributed at least some data, 190 returned both the mothers’ and fathers’ Dads Active Disease Support scale (DADS). There were some missing data on other measures, hence the varied samples sizes depending on the analysis. Of the 34 noncompleters, 31 were missing fathers’ DADS scores. The only significant demographic difference between the completers and the noncompleters was that the noncompleters had significantly higher socioeconomic status (SES; Hollingshead mean
48.3 vs. 45.2). There were no significant differences in any of the outcome measures between completers and noncompleters.

Within this sample, 168 fathers (88%) and 180 mothers (95%) were biological parents of the index child. Other caregivers who participated included step-parents, adoptive parents, and unmarried companions. Nonbiological caregivers, also referred to as “mothers” and “fathers” in this article, must have resided with the chronically ill child for at least 6 months to participate. Each participant signed an institutionally approved informed consent form before beginning the research procedures. No data is available on the nonparticipants due to Health Insurance Portability and Accountability Act (HIPAA) regulations. Thus, no analytic comparisons of participants versus nonparticipants could be performed.

**Measures**

**Demographic Information**

Caregivers were interviewed together to obtain the following demographic information: age, education, occupation, race/ethnicity, and marital status of each caregiver; family composition; the child’s age, sex, race/ethnicity, type and date of diagnosis of chronic disease; and the number of hospitalizations and emergency room visits in the prior 6 months (Table I). The Hollingshead Four Factor Index of Social Status (Hollingshead, 1975; unpublished data) was calculated based on caregivers’ reports of their education and occupation.

The following measures were completed independently by mothers and fathers:

**Dads’ Active Disease Support Scale**

The DADS is a 24-item Likert type scale with separate forms for mothers and fathers (Wysocki & Gavin, 2004). The items ask about the father’s participation in typical illness management tasks common to pediatric chronic disease. The Mothers’ form of the DADS asks about how much the male partner is involved in illness-related tasks, then asks how that level of involvement affects the family’s illness-related coping. The mother is asked to consider the past 6 months. The Fathers’ form of the DADS seeks the father’s assessment of his own involvement in each of the same tasks.

For “Amount” items, caregivers were asked “When it was needed, how much has he (have you) done this in the past 6 months?” For both forms of the measure, response options were 1, “0%”; 2, “25%”; 3, “50%”; 4, “75%,” and 5, “100%.” For “Helpfulness” items, caregivers were asked, “Has this made family coping with the disease harder or easier?” Response options were 1,
“Harder”; 2, “Neither Harder Nor Easier”; 3, “Slightly Easier”; 4, “Easier”; and 5, “Much Easier.” Caregivers’ responses yielded separate scores for “Amount” and “Helpfulness” of father involvement. For 17.4% of DADS items, caregivers reported that the behavior of interest had not been needed in the prior 6 months. In such instances, participants were given a prorated “Amount” score consisting of the mean score for all completed Amount items multiplied by 24. A score of 2 (“Neither Harder Nor Easier”) was entered for all Helpfulness items when the caregiver reported that the behavior in question was not needed in the prior 6 months.

Wysocki and Gavin (2004) report extensive psychometric data on the DADS. In this study, alphas for the mother-reported scales ranged from .92 to .95 and for father-reported scales ranged from .89 to .92. Test–retest reliability over one month ranged from .78 to .86 for mothers’ scores and from .75 to .82 for fathers’ scores.

**Family Assessment Device**
The Family Assessment Device (FAD; Epstein, Baldwin, & Bishop, 2000) is a widely used 60-item Likert-type scale that assesses 6 dimensions of family functioning (Responsiveness, Behavior Control, Communication, Problem Solving, Affective Involvement, and General Functioning). The reliability and validity of the instrument have been verified in multiple studies (Epstein et al., 2000). In this study, only the General Functioning Scale will be reported, with alphas of .83 for mothers and .82 for fathers.

**Impact on Family Scale**
The Impact on Family Scale (IFS; Stein & Reissman, 1980) is a 24-item scale on which parents rate the extent to which a pediatric medical condition has had an impact on the family. The instrument yields a total score and 4 subscales: Financial (+ items); Familial/Social (9 items); Personal Strain (6 items), and Mastery (5 items). In this study, only the total score will be reported with alphas of .89 for mothers and .86 for fathers.

**Dyadic Adjustment Scale**
The Dyadic Adjustment Scale (DAS; Spanier, 1976) is a widely utilized and well-validated 32-item measure of marital functioning and satisfaction. It yields a global measure of marital well being, as well as subscales for the following dimensions of marital functioning: Consensus, Satisfaction, Cohesion, and Affectional Expression. In this study only the Global Score will be reported, with alpha’s of .94 for mothers and .93 for fathers.

The following two measures were completed by mothers only:

**Parenting Stress Index, Brief Form**
The Parenting Stress Index, brief form (PSI; Abidin, 1983) is a well-validated and widely used tool for evaluating the level of stress prevailing in a specific parent–child relationship. The instrument yields a norm-referenced score for total Parenting Stress, as well as scale scores for Parental Distress, Parent–Child Dysfunctional Interaction, and Difficult Child. We employed the Total Parenting Stress score, with an alpha of .93.

**Brief Symptom Inventory**
The Brief Symptom Inventory (BSI; DeRogatis, 1983) is a condensed version of the well-validated Symptom Checklist 90-R. It is a widely used checklist that obtains patients’ reports of the frequency and severity of 53 common psychiatric symptoms over the prior week. The instrument yields a standardized Global Severity Index as well as standardized scores for the following 9 categories of symptoms: Depression, Anxiety, Hostility, Interpersonal Sensitivity, Somatic Complaints, Obsessive–Compulsive, Phobic, Paranoia, and psychosis. For the purposes of this study, only the Global Severity Index will be reported, with an alpha of .95.

**Procedures**
Potential participants were identified via clinic schedules at Nemours Children’s Clinics in Jacksonville and Orlando, Florida. Parents of children scheduled for clinic visits for one of the targeted diagnoses within the coming 6 months were mailed a study description that delineated the eligibility requirements and instructions for contacting the Project Coordinator. In the case of PKU, the small available sample of families at the two sites led the investigators to advertise the study on a PKU-related internet website. With either recruitment method, after verifying the family’s eligibility, the Project Coordinator scheduled the family for study participation. Each member of a couple could participate in one of two ways: either in person or with a combination of telephone interview and questionnaires returned by mail. Participation through these various means was utilized to increase convenience and thus increase the probability of father involvement. Fourteen percent of couples came to the clinic, 59% chose mail/phone interview, and in 27% of the couples one member came in person, whereas the other chose mail/phone interview. The manner of data collection was not associated with either mothers’ or fathers’ scores on the DADS (Wysocki & Gavin, 2004). After family members read and signed
the informed consent form, they independently and confidentially completed the questionnaires and interview items required of each. Each couple was paid $50 after the required measures were completed and returned. The Project Coordinator reviewed the returned questionnaires carefully to ensure that every item was completed and any administration errors were corrected before the data were entered.

All data entry and statistical analyses were completed using SPSS 11.5 for Windows. All questionnaires were formatted to enable machine scoring using an Opscan 4 optical scanner (NCS-Pearson, Inc.), enabling direct export of data to an SPSS data file. Distributions of all study variables were checked for normality and no data transformations were necessary to achieve normal distributions.

Results

Initial Analyses

Sample Characteristics

Table I summarizes the demographic characteristics of the enrolled sample. Overall, the participants appeared to be broadly representative in terms of the child’s medical diagnosis, age and gender and of parental age, education, and employment. Initial analyses exploring possible difference among the disease groups found no significant differences across medical diagnoses on any of the outcome measures. Among the 190 participating couples who contributed complete data sets, the distribution of Hollingshead Four Factor Index social status categories was: Low, “3 (1.6%)”; Lower Middle, “13 (6.9%)”; Middle, “49 (25.8%)”; Upper Middle, “79 (41.6%),” and “Upper, 46 (24.1%).” The mean Hollingshead Index raw score of 43.3 indicates that the average couple was from the middle socioeconomic class, and this score does not differ significantly from that of 241 two-parent families that have participated recently in similar research at this same institution (mean = 44.7). Correlational analyses showed that higher SES was weakly associated with less paternal involvement as reported by fathers but not mothers (please see Wysocki & Gavin, 2004 for more extensive discussion of these findings) and unrelated to any of the outcome measures except for the Parenting Stress Index ($r = .21, p = .004$). Therefore, we did not treat SES as a covariate in the analyses reported here.

Associations Among DADS Scores and Measures of Maternal Adjustment

First, the distributions of DADS Amount and Helpfulness scores were used to assign mothers and fathers by tertile split into those with High, Moderate, or Low DADS scores (Means and standard deviations of the DADS Amount and Helpfulness scores from this sample are available in Wysocki & Gavin, 2004). To evaluate the associations among DADS scores and the BSI Global Severity Index and Parenting Stress Index total score, separate ANOVA procedures were performed treating the DADS Amount and Helpfulness tertiles as between-subject factors. Tables II and III summarize the associations

<table>
<thead>
<tr>
<th>Scale</th>
<th>DADS Amount tertile</th>
<th>DADS Helpfulness tertile</th>
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<tr>
<td></td>
<td>Low</td>
<td>Moderate</td>
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<tr>
<td>Parenting Stress Index (total score)</td>
<td>F(2, 185) = 8.85, $p = .0001$</td>
<td>F(2, 185) = 14.36, $p = .0001$</td>
</tr>
<tr>
<td>Brief Symptom Inventory (Global Severity Index)</td>
<td>$F(2, 180) = 2.12, p = .12$</td>
<td>$F(2, 185) = 4.02, p = .02$</td>
</tr>
<tr>
<td>Dyadic Adjustment Scale (total score)</td>
<td>$F(2, 185) = 2.39, p = .09$</td>
<td>$F(2, 185) = 2.39, p = .09$</td>
</tr>
<tr>
<td>Impact on Family Scale (total score)</td>
<td>$F(2, 172) = 10.17, p = .0001$</td>
<td>$F(2, 172) = 13.89, p = .0001$</td>
</tr>
<tr>
<td>Family Assessment Device (general functioning scale)</td>
<td>$F(2, 185) = 5.84, p = .003$</td>
<td>$F(2, 185) = 5.84, p = .003$</td>
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ANOVA, analysis of variance; DADS, Dads Active Disease Support scale.
among mothers’ and fathers’ DADS tertiles, respectively, and measures of maternal psychological adjustment (BSI Global Severity Index) and parenting stress (Parenting Stress Index).

For mothers’ DADS Amount tertiles, no significant effects were obtained on the BSI Global Severity Index. For mothers’ DADS Helpfulness tertiles, significant effects were obtained on the Global Severity Index (p = .02), and post hoc analyses confirmed that more helpful paternal involvement was associated with more favorable maternal psychiatric adjustment. For fathers’ DADS tertiles, no significant effects were obtained.

For the Parenting Stress Index, the main effect for fathers’ amount scores approached significance (p = .07), whereas the effect for mothers’ amount scores was not significant. Similarly, for Helpfulness, there was a trend toward statistical significance for mothers (p = .09), whereas the effect for fathers was not significant.

### Associations Among DADS Scores and Measures of Marital and Family Functioning

To evaluate the associations among DADS scores and measures of marital and family functioning, several one-way analyses of variance (ANOVA) were performed using procedures parallel to those described above. Mothers’ and fathers’ assignments to tertiles of DADS Amount and Helpfulness scores again served as between group factors in these analyses. These ANOVAs included separate analyses of mothers’ and fathers’ DADS Amount and Helpfulness scores on the total score on the DAS, the total score on the IFS, and the General Functioning Scale of the FAD. Tables II and III summarize the associations among mothers’ and fathers’ DADS tertiles, respectively, and scores on these measures.

For the DAS, significant effects were obtained for mothers’ DADS Amount and Helpfulness (p’s = .0001, respectively). For fathers (Table III), a significant effect was obtained for the DADS Helpfulness score (p = .05). The father’s Amount scores approached significance (p = .055). Post hoc comparisons showed that higher DADS scores were associated with better marital functioning in each case.

For the IFS, a significant effect was obtained for mothers’ DADS Amount and Helpfulness scores (p’s = .003, respectively) Post hoc analyses showed that higher DADS scores were associated with less impact of the disease on the family. For fathers no significant effects were obtained on this scale.

For the FAD General Functioning Scale, significant effects were obtained for mothers’ DADS Amount and Helpfulness scores (p’s = .0001, respectively). Higher mothers’ DADS scores were associated with more favorable family functioning. For fathers (Table III), significant effects were also obtained for DADS Amount and Helpfulness (p = .003 and p = .0001, respectively). Again, higher fathers’ DADS scores were associated with more favorable family functioning.

### Discussion

The results of this study support the hypothesis that mothers’ reports of paternal involvement were associated
With better maternal, marital, and family outcomes. For father-reported data, the results supported a relation between fathers' report of their own involvement with marital satisfaction and family adjustment but not with mother's self-reported psychological adjustment. These results provide some support for the hypothesis derived from the Wallander, Varni, Babani, Banis, et al. (1989) Risk and Resistance Model that paternal involvement served as a resistance factor that promoted more effective coping with parenting stress, healthier family functioning, and better marital satisfaction.

As predicted, an association was found between mothers' ratings of paternal helpfulness and maternal psychological symptoms as measured by the Brief Symptom Inventory. These relations may be bidirectional. That is, mothers with better adjustment may be better at eliciting supportive help from their husbands. In turn, women who enjoy more support from their spouses may experience less stress and distress.

There was an absence of significant associations among fathers' DADS scores and mothers' BSI and PSI scores. The absence of significant associations between fathers' reports of their own involvement in care with mothers' reports of their own psychiatric symptoms and parenting stress may be due to the fact that we have attempted to demonstrate relations between conceptually distinct constructs, each of which was reported by a different respondent. By contrast, fathers' DADS scores were more consistently related to their own reports of their relationship satisfaction (DAS), the impact of the medical condition on their families (IFS) and general family functioning (FAD).

Although some previous studies have shown no relation in general between chronic childhood illness and marital or family distress (Sabbeth & Leventhal, 1984), others have found such a relation. Within the context of social support and, specifically, the degree to which the father supports the mother in concrete illness-related tasks, more help appears to positively affect the marital relationship (Barbarin et al., 1985). In this study, the associations between father involvement and marital and family functioning were clear and consistent. In the domain of marital adjustment, mothers and fathers both reported that more father involvement was associated with better marital functioning as reported on the DAS. This is consistent with other reports of associations between paternal support and marital satisfaction (Quittner et al. 1998). Greater paternal involvement in the medical regimen might enhance marital communication and satisfaction with the partner. Mothers who receive more help may experience less role strain, and may experience less frustration with their partners. Succeeding at such a challenge might have the effect of drawing the parents closer to one another, further enhancing their marital functioning and satisfaction. Our findings are consistent with others who have found that lack of spousal involvement and inequity in task distribution place a couple at risk for impaired marital satisfaction (Taanila, Kokkonen, & Jarvelin, 1996).

Alternatively, it is important to consider that prevailing levels of marital and family satisfaction may influence spouses' perceptions of paternal involvement. For example, a wife experiencing high marital satisfaction might be more likely to perceive her husband as more involved and helpful. In reality, couples enjoying high marital satisfaction are likely to view each other more positively and be more prepared to collaborate effectively in complex disease management tasks.

Father involvement was also found to be related to how the family as a whole functions. In terms of how the family copes with illness-related stress, the mother's view of father involvement was related to the total score on the IFS. These findings suggest that more paternal involvement may buffer families from the adverse effects of the stress, role strain, and treatment burden that accompany the management of pediatric chronic diseases.

These patterns were even stronger when looking at general family functioning as measured by the FAD. Both mothers and fathers reported that higher DADS scores were associated with more favorable family functioning on the FAD. These results are consistent with previous studies that highlight the importance of father involvement in families with chronically ill children. For example, studies by Hanson et al. (1988) and Harris et al. (1999) suggest that children from “father-absent” families tend to demonstrate poorer treatment adherence and health status.

This article is a first step in looking more carefully at the role of fathers in the disease management process, but the generalizability of the work is limited by a number of issues. First, the sample is primarily Caucasian and middle class. By choosing to look at two-parent families, we recognize that we have limited the range of our SES, as SES tends to be higher in two-parent households. It would be interesting and important to study whether these findings could be replicated in a study specifically focusing on two-parent families of low SES. That said, preliminary analyses performed in this study did indicate that SES was unrelated to all outcome measures except the Parenting Stress Index, suggesting that SES is unlikely to be a strong factor. However, it would be
important to pursue this further in a more broadly representative sample.

It is important to consider what future research directions might be fruitful. Most important would be a longitudinal study examining the role of fathers over time. This would not only allow us to explore causal directions of variables but would also enable us to look at how fathers’ roles change over time, and how they might be related to the developmental level of the child. Inclusion of other variables such as external sources of support and age at diagnosis, not included in this study, would be helpful. Exploring relations between father involvement in illness management and marital communication and satisfaction with one’s spouse would also be worthwhile. Inclusion of qualitative interviews on how mothers and father’s perceive the fathers’ roles would further add to our understanding of their important contribution. Such a qualitative study might shed light on what kinds of support mothers as “illness managers” find most important or useful in the family.

These results indicate that paternal involvement is associated with favorable status on diverse maternal, marital, and family outcomes. Once the direction of effect is validated in a longitudinal study, we can explore how to intervene in families to maximize both the quantity and quality of paternal involvement to promote family adaptation to this challenge.

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