

# Paternal Involvement in the Management of Pediatric Chronic Diseases: Associations with Adherence, Quality of Life, and Health Status

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**Objectives** This article reports associations among paternal involvement in pediatric chronic disease management and child outcomes. **Methods** The Dads' Active Disease Support scale (DADS) and measures of treatment adherence, quality of life, health status, and health care utilization were obtained for youths with six chronic diseases, with complete data sets obtained from 190 couples. **Results** Paternal involvement was not associated with these outcomes among younger children. Among adolescents, mother-reported and father-reported DADS scores indicating more paternal involvement were associated with maintenance, rather than deterioration, of treatment adherence and more favorable quality of life. Youths' health status and health care utilization were not related significantly to paternal involvement. **Conclusions** More paternal involvement was associated with more favorable adherence and quality of life among adolescents but not associated with health status or health care utilization. Longitudinal studies could verify whether paternal involvement merits clinical intervention.

**Key words** coping; fathers; involvement; pediatric chronic disease.

Studies of the impact of childhood chronic illness on the family have tended to focus on mothers both as study participants and as the focus of investigation. Mothers bear the brunt of the practical (e.g., Anderson, Auslander, Jung, Miller, & Santiago, 1990; Etwiler, 1962; Quittner, Pipari, Regoli, Jacobsen, & Eigen, 1992) and emotional (e.g., Goldbeck, 2001; Kovacs et al., 1990; Timko, Stovel, & Moos, 1992) burdens of illness management. In the past decade, however, investigators have begun to explore the father's role and include the father's perspective when studying these families (Drotar, 1997; Quittner, Pipari, et al., 1992; Seiffge-Krenke, 2002). Several studies show that youths with chronic diseases from father-absent families may demonstrate poorer treatment adherence, psychological adjustment, and health status when compared with those from father-present families (Hanson, Henggeler, Rodrigue, Burghen, & Murphy, 1988; Harris, Greco, Wysocki, Elder-Danda, & White, 1999). Other studies demonstrate that measures

obtained separately from mothers and fathers may have different associations with medical and psychosocial outcomes of children with chronic medical conditions (e.g., Goldbeck, 2001; Schobinger, Florin, Zimmer, Lindemann, & Winter, 1992; Timko, Stovel, Moos, & Miller, 1992; Wysocki, 1993), underscoring the importance of obtaining multiple perspectives.

There has been an increase in research on the role of fathers in child development (Booth & Crouter, 1998; Lamb, 1997; Schwebel & Brezaussek, 2004), but the actual involvement of fathers in pediatric chronic disease management has received little attention. Although studies have shown that mothers assume most disease management responsibility (e.g., Quittner, DiGirolamo, Michel, & Eigen, 1992), there is probably considerable variability among families in the extent to which fathers offer instrumental and emotional forms of support. The quantity and quality of paternal involvement may directly affect such processes as monitoring of children's

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treatment adherence, timeliness of symptom recognition, frequency of positive reinforcement for children's self-management behaviors, and the acquisition of information about the disease and its treatment. Indirect effects of paternal involvement on child outcomes may include enhancement of youth's stress management and coping skills, facilitation of school performance and adjustment, and increased opportunities for supervised recreational activities. To the extent that paternal involvement influences family coping with children's chronic medical conditions (Wallander, Varni, Babani, Banis, & Wilcox, 1989), it may prove to be an important target for clinical interventions designed to promote family adaptation to these challenges.

Wallander et al. (1989) proposed a "Risk and Resistance Model" to predict children's psychological adjustment as a function of maternal and family adaptation to pediatric chronic illnesses and handicapping conditions. Their model proposes that the manifestation of the adverse effects of certain risk factors (e.g., parameters of the disease/disability, functional independence, and psychosocial stressors) on children's psychosocial 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. This research can be viewed in the context of the Wallander et al. (1989) Risk and Resistance Model as an examination of the contributions of several specific social-ecological resistance factors. An implication of this model is that the amount and helpfulness of paternal involvement in pediatric chronic disease management are likely to influence child adaptation to this psychological stress. In this article, measures of treatment adherence and quality of life are viewed as indices of "child adaptation."

When framed by the conceptual model offered by Wallander et al. (1989), paternal involvement could function as a coping resource that influences both mothers' and children's appraisals of their adaptive capacity, access to emotional and affiliative forms of social support, range of problem solving alternatives, and tangible or instrumental forms of support. In a separate article (Gavin & Wysocki, in press), we have reported that paternal involvement was associated with more favorable status on multiple dimensions of maternal psychological functioning, parenting stress, marital satisfaction, and family coping with disease management. This article extends the analysis of data obtained from the same

sample of parents by investigating whether paternal involvement in the management of pediatric diseases was associated with several child outcomes. Specifically, we hypothesized that higher quantity and/or quality of paternal involvement would be associated with (a) higher levels of medical treatment adherence, (b) more favorable quality of life, (c) more favorable health status, and (d) less health care utilization as measured by the frequencies of emergency room visits and hospitalizations. There was no a-priori empirical or theoretical reason to anticipate that mothers' and fathers' reports of paternal involvement would be related differentially to the child outcomes, and so no hypotheses were extended in that regard.

## Method

### *Research Design and Participants*

This study utilized a cross-sectional, correlational design to address the research objectives outlined above. 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, all 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. In addition to couples with intact marriages (86% of the sample), participating caregivers also included 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 being treated 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. From an initial pool of 374 potentially eligible families who were approached about the study through two participating pediatric subspecialty clinics, 224 couples (mothers or other female caregivers and fathers or other male caregivers) agreed to participate, and complete data sets were obtained from 190 couples. Each participant signed an institutionally

approved informed consent form before contributing any data. Some participants failed to complete and return every measure, resulting in different sample sizes entering the various statistical analyses.

The mean ( $\pm 1$  SD) ages of the study participants were for child age,  $10.2 \pm 4.6$  years; for maternal age,  $38.5 \pm 6.7$  years; and for paternal age,  $40.8 \pm 7.6$  years. Gender of the index child was 49% male and 51% female. Parent-reported race/ethnicity was 86% Caucasian, 7% African-American, 2% Hispanic, 1% Asian/Oriental, and 3% Other/multiracial. Family composition of the study families was both biological parents (86%), one biological parent and one stepparent (11%), and adopted (2%). The proportion of children with each medical condition was asthma (18%), cystic fibrosis (18%), diabetes (19%), inflammatory bowel disease (13%), PKU (18%), and spina bifida (12%). The mean Hollingshead (1975) Four-Factor Index raw score was  $45.3 \pm 11.7$ , and the distribution of socioeconomic classes was 3 low (1.6%), 13 lower middle (6.9%), 49 middle (25.8%), 79 upper middle (41.6%), and 46 upper (24.1%). Single-parent family composition is associated strongly with low socioeconomic status, and so it is not surprising that this sample of two-parent families would exhibit higher socioeconomic status than might be typical of studies enrolling families with more varied family composition. The mean Hollingshead Four Factor Index raw score of 45.3 for this sample indicates that the average couple was from the middle socioeconomic class. This score does not differ significantly from that of 241 two-parent families that have participated recently in similar research at this same institution ( $M = 44.7$ ). The mechanism of questionnaire completion and data collection (mail or in-clinic) did not significantly affect either mothers' or fathers' scores on the Dads' Active Disease Support scale (DADS).

### Measures

Measures of maternal adjustment, marital and family function, and child outcomes were obtained, but only those pertinent to this article are described here. Descriptive statistics and internal consistency estimates for each measure based on data from this sample are summarized in Table I. Caregivers completed certain measures together to maximize accuracy of reporting [i.e., Demographic Information Form, Disease-Specific Self-Management Profiles (SMP), Pediatric Quality of Life Inventory (PedsQL)]. The DADS was completed independently by mothers and fathers.

### Demographic Information Form

This brief questionnaire captured data on caregiver education and occupation, race/ethnicity, family composition,

the patient's age, sex, type, and date of diagnosis of chronic disease, and health care utilization (hospitalizations, emergency room visits) in the prior 6 months. The Hollingshead Four-Factor Index of social status was calculated based on caregivers' reports of their education and occupation.

### DADS

The DADS is a 24-item Likert type scale with separate forms for mothers and fathers who were instructed to complete the measure independently. Respondents could indicate that a given task was not necessary during the prior 6 months and skip that item, which occurred for 17.4% of possible DADS responses. The items describe 24 specific family tasks in managing any pediatric chronic disease and include two questions about each task. First, respondents rated the frequency with which the father performed that task in the prior 6 months on a five-choice Likert scale ranging from 1, "never" to 5, "always." Then, respondents rated the degree to which the father's involvement was helpful in promoting family coping with the illness, again on a five-choice Likert scale ranging from "harder" to "much easier." These sets of responses yielded separate scores for "amount" and "helpfulness" of father involvement, respectively, each with a possible range of 24–120. A total score, consisting of the sum of the amount and helpfulness scores, can also be calculated, with a possible range of 48–240. If items were "skipped" because the indicated task was unnecessary in the prior 6 months, the participant received a prorated DADS amount score consisting of the average score on all completed amount items multiplied by 24. Ratings of helpfulness that were skipped for the same reason were scored as "neither helpful nor harmful." In a separate article (Wysocki & Gavin, 2004), we have reported a detailed analysis of the psychometric properties of the DADS based on data obtained from this sample, including the confirmation of acceptable internal consistency (alpha coefficient for all scales  $\geq .92$ ), test-retest reliability over 1 month (range .75–.86), construct validity (using confirmatory factor analysis), and convergent validity (significant positive correlations with the Family Assessment Device General Functioning subscale). The correlations between DADS amount and helpfulness scores were .74 for mothers and .61 for fathers ( $p < .0001$  in both cases).

### SMP

To enable comparison between and within diagnoses, each couple participated in a disease-specific structured interview to assess medical treatment adherence. Total raw scores on these measures were converted into the

**Table I.** Mean and Standard Deviation and Internal Consistency (Cronbach's Alpha Coefficient Where Applicable) for Total and Subscale Scores for Each Administered Questionnaire Based on the Present Sample of Participants

Measures completed separately by mothers and fathers	Mothers		Fathers	
	<i>M (SD)</i>	$\alpha$	<i>M (SD)</i>	$\alpha$
Dads' Active Disease Support Scale				
Amount of support	64.9 (20.5)	.94	66.6 (18.0)	.92
Helpfulness of support	75.8 (21.9)	.95	70.6 (18.2)	.95
Total	141.0 (39.6)	.95	137.3 (30.6)	.93
Measures completed jointly by mothers and fathers	<i>M (SD)</i>	$\alpha$		
Pediatric Quality of Life Inventory total score	6.5 (5.1)	.83		
Self-management profile (% of possible points)				
Asthma	77.7 (8.6)	.77		
Cystic fibrosis	78.2 (13.4)	.71		
Diabetes	78.5 (9.1)	.82		
Inflammatory bowel disease	81.7 (10.4)	.66		
Phenylketonuria	85.9 (9.0)	.73		
Spina bifida	88.5 (6.9)	.66		
Measures of health status and health care utilization	%			
Subjective ratings of health status				
Exceptionally well	13.8			
Better than average	27.7			
About the same	25.0			
A little worse	14.3			
Much worse	1.8			
Frequency of hospitalizations				
0	88.4			
1	7.4			
2	2.6			
3	1.6			
Frequency of emergency room admissions				
0	89.5			
1	5.3			
2	3.2			
3	0.5			
4	1.1			
5	0.0			
6	0.5			

percentage of possible points earned, thus reflecting treatment adherence on a common quantitative dimension across diagnoses.

The Diabetes Self-Management Profile (DSMP) is an adaptation of the diabetes adherence interview developed by Hanson, Henggeler, and Burghen (1987), which was modified to enable assessment of the flexible self-management skills that are central to modern intensified therapy for diabetes. The 23-question structured interview yields a total score and subscale scores for five dimensions of the diabetes regimen (management of hypoglycemia; diet, exercise, blood glucose testing, and insulin administration and adjustment). Harris et al. (2000) reported strong psychometric properties for this

interview, including a moderate correlation ( $r = .40$ ) between the average total score and HbA<sub>1c</sub> levels over 18 months follow-up in a sample of 142 patients.

For this study, the authors constructed similar structured interviews for cystic fibrosis, asthma, spina bifida, PKU, and inflammatory bowel disease that were parallel in format to the DSMP interview (Harris et al., 2000). Item content was developed with pediatric subspecialists and nurse practitioners at both sites, and wording of questions and associated scoring criteria were reviewed repeatedly by these consultants until a consensus was achieved for item content and wording. In each case, questions regarding adherence with specific regimen components were introduced by the interviewer

with remarks indicating that many youths struggle with doing these tasks perfectly and consistently. Interviewers were taught to refrain from judgmental responses to admissions of nonadherence. As summarized in Table I, internal consistency of each disease-specific adherence interview, as measured by the alpha coefficient, ranged from .66 to .82 across the six medical conditions. In addition, the validity of these adherence measures was evaluated by calculating Pearson correlations between the adherence score and a disease-specific objective measure of health status. For each medical condition, these correlations were asthma ( $r$  with forced expiratory volume = .29,  $p = .07$ ), cystic fibrosis ( $r$  with forced expiratory volume = .08,  $p > .10$ ), diabetes mellitus ( $r$  with glycosylated hemoglobin = -.44,  $p < .03$ ), PKU ( $r$  with serum phenylalanine = -.38,  $p = .05$ ), and spina bifida ( $r$  with frequency of urinary tract infections in prior 6 months = -.37,  $p = .04$ ). Pearson correlation between the adherence score and the subjective health status index obtained for the full sample in this study was also statistically significant ( $-.22$ ;  $p < .003$ ). With socioeconomic status controlled, the diagnostic groups did not differ significantly in adherence scores.

#### PedsQL

The PedsQL (Varni, Seid, & Rode, 1999) consists of a 15-item core measure of generic quality of life and 8 supplemental modules that assess disease- and treatment-specific domains. Psychometrically equivalent interview or self-report formats are available. Only the 15 core items were administered in this study. The PedsQL was "reverse scored" for this article such that higher scores indicated more favorable quality of life. With socioeconomic status controlled, PedsQL total scores did not differ significantly among diagnostic groups.

The following measure was obtained from health professionals involved in the child's care.

#### Youth's Subjective Health Status

Although objective indices of children's health status were obtained for this study, analyses that cut across medical conditions necessitated derivation of a health status measure that was applicable to all conditions. It was felt that standardizing objective health status measures by  $z$ -score transformation was an inadequate solution to this problem. Hence, subjective health status ratings were obtained to permit comparisons of children's outcomes across the six chronic diseases. Specifically, children's health status was assessed using subjective ratings of health status by the health care provider who was most familiar with the child's medical status relative

to the index condition. A pediatric subspecialist physician, physician's assistant, or nurse practitioner who was very familiar with the child's medical condition and its management rated the patient according to this single-item scale: "Given the objective features of this child's chronic disease, which of the following best describes this child's current health status:

- The child is doing exceptionally well compared to similar patients
- The child is doing better than average for similar patients
- The child is doing about the same as similar patients
- The child is doing a little worse than similar patients
- The child is doing much worse than similar patients."

Scores on this subjective health status index did not differ among diagnostic groups.

#### Health Care Utilization

Health care utilization was measured by parental report of their children's hospitalizations and emergency room visits in the prior 6 months. Both the number of distinct hospitalizations and the number of days hospitalized during each admission were recorded. Direct confirmation of these events was not possible because hospitalizations and emergency room admissions could occur at multiple medical centers other than those at which the study was conducted.

#### Procedures

Potential participants were identified by searching clinic schedules at two pediatric medical centers in Florida. Legal caregivers 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. A total of 374 couples were contacted, of whom 224 couples (59%) enrolled in the study and completed some study measures and 190 (51%) returned both the mother's and father's form of the DADS. The occurrence of missing data was not systematically related either to specific measures or to maternal or paternal respondents. Completion of the DADS occurred in person (31%), by mail (63%), or by telephone interview (6%). Mail and telephone

participation were utilized to increase convenience to facilitate the involvement of fathers. After both caregivers read and signed an informed consent form, they completed confidentially the questionnaires and interview items required of each. Within 5 days of distributing the questionnaire packet, the project coordinator telephoned the caregivers to complete the disease-specific structured interview to obtain a measure of medical treatment adherence for their child and the PedsQL questionnaire. Both caregivers were interviewed together either by telephone or in person for the completion of these two measures, and any discrepancies between their responses were resolved by the interviewer to achieve a consensus on each item. At that time, the caregivers were reminded to complete and return the DADS scale if they had not already done so. 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.

### Statistical Analysis

Data entry and statistical analyses were completed using SPSS 11.5 for Windows. All questionnaires were formatted to enable automated scoring using an OpScan 4 optical scanner (NCS-Pearson) at one of the centers, enabling direct export of data to an SPSS data file. Distributions of all study variables were checked for normality, and it was determined that no data transformations were needed to achieve normal distributions. Adequate variability was evident in the distributions of scores for all study variables.

For the purposes of this report, DADS amount, helpfulness, and total scores were computed separately for each caregiver. Because the DADS amount and helpfulness scores were both highly correlated with the DADS total scores ( $r = .92$  and  $.93$ , respectively, for mothers and  $r = .88$  and  $.90$ , respectively, for fathers), only the DADS amount and helpfulness scores were used in the analysis of the study results. The resulting DADS scores were used to assign caregivers by tertile split into those reporting high, moderate, and low amount or helpfulness of paternal involvement in disease management. Although a multiple regression analytic approach would preserve DADS scores as a continuous variable, the ANOVA approach that we used was preferred because it facilitated the presentation of the findings in a more easily comprehensible manner. Both approaches reduce to efforts to partition the variance in a dependent variable that is caused by main and interaction effects among specified independent variables.

The general conclusions when using the two methods were virtually identical. Combining the six diagnostic groups into one sample was justified because, with socioeconomic status controlled statistically, there were no statistically significant differences between diagnostic groups on the DADS or any of the outcome measures. Because many of the child outcome variables were associated with child age, consistently in the direction of deteriorating status with increasing age, youth were assigned to one of four age groups:  $<6$  ( $n = 42$ ),  $6-11$  ( $n = 46$ ),  $12-14$  ( $n = 54$ ) and  $>14$  ( $n = 48$ ). No specific a-priori hypotheses were extended regarding the relationship of age to the outcome measures or the interaction of age with paternal involvement. The four age groups and the caregivers' DADS amount and helpfulness score categories then served as between-subject variables in separate analyses of variance designed to evaluate the effects of mothers' and fathers' ratings of paternal involvement on youth's treatment adherence, quality of life, and health outcomes and the differences in these associations as a function of the child's age group. Although the inclusion of socioeconomic status as a covariate or additional between-subjects factor was considered, we concluded that this would reduce the statistical power unacceptably.

## Results

Table I summarizes the mean scores obtained on the DADS, the SMP, and the PedsQL for this sample, as well as estimates of internal consistency (alpha coefficient) for these measures. Also summarized in Table I are descriptive data on health status and health care utilization for this sample. The statistical analyses of the associations among mothers' and fathers' DADS scores and the various child outcomes are described below.

### *Association of DADS Scores with Treatment Adherence (Self-Management Profiles)*

Separate  $3 \times 4$  analyses of variance were completed with mother-reported and father-reported DADS amount and helpfulness tertiles and age groups as the between-subject variables and the youth's percentage of possible points on the SMP as the dependent variable. For mothers, neither the main effect for DADS helpfulness,  $F(2, 182) = 2.43$ ,  $p = .09$ , nor the interaction of DADS helpfulness with age group,  $F(6, 182) = 0.71$ ,  $p = .64$ , were significant. However, a significant age  $\times$  DADS tertile interaction effect was obtained for DADS amount,  $F(6, 184) = 2.90$ ,  $p < .05$ . For fathers as well, neither the main effect for DADS helpfulness,  $F(2, 181) = 2.57$ ,  $p = .08$ , nor the interaction of DADS helpfulness with age,  $F(6, 181) = 0.91$ ,

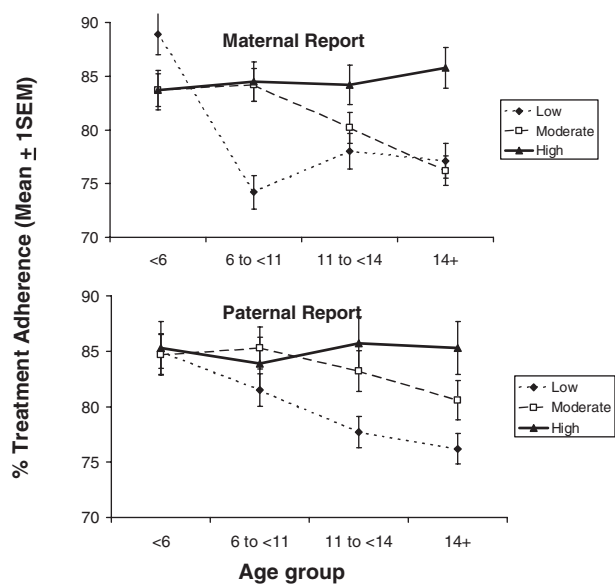
$p = .49$ , were significant. However, a significant age X DADS tertile interaction effect was obtained for DADS amount,  $F(6, 181) = 2.93, p < .05$ .

Figure 1 illustrates these interactions for mother-reported and father-reported DADS amount scores, showing that treatment adherence, expressed as the percentage of possible points earned, decreased with increasing age of the child for those with DADS amount scores in the low and moderate tertiles, but no such decrease was evident for those with DADS scores in the high tertile. Post-hoc comparisons showed that, for those over 14 years of age, adherence scores in the high DADS amount tertile were significantly higher than those in either the low or moderate tertiles. Within the three younger age groups, adherence scores did not differ significantly among the DADS amount tertiles. No similar relationships were found for DADS helpfulness scores.

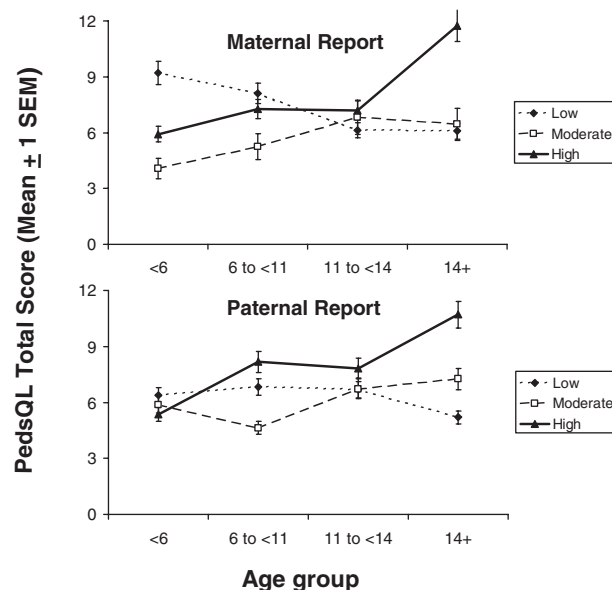
### Association of DADS Scores with Youth's Quality of Life (PedsQL)

Corresponding  $3 \times 4$  analyses of variance were also completed with DADS amount and helpfulness tertiles and age group as the between-subject variables and the total score on the PedsQL as the dependent variable. Note that higher scores indicate more favorable parental reports of their children's quality of life. Again, the main effects for DADS amount and helpfulness tertiles were

not significant for either mother-reported or father-reported DADS scores. The main effect for age groups was not statistically significant,  $F(3, 185) = 1.19, p = .34$ , with post hoc analyses showing more favorable quality of life among adolescents  $\geq 14$  years old compared with the three younger age groups. The age group X DADS amount interaction effect was significant for both mothers,  $F(6, 182) = 2.33, p < .035$ , and fathers  $F(6, 181) = 2.47, p < .03$ . Figure 2 portrays this interaction, showing that PedsQL scores for the three younger age groups were independent of level of paternal involvement but, among youth over 14 years old, adolescent quality of life was highest among those with the most paternal involvement in disease management. Among the adolescents over 14 years of age, mean PedsQL total scores were 11.7 for high, 6.4 for moderate, and 6.1 for the low DADS amount tertiles among mothers, a difference that was statistically significant,  $F(2, 45) = 5.17, p < .01$ . Essentially, the same pattern of findings emerged for fathers' DADS scores. PedsQL scores did not differ significantly among youth below 14 years of age as a function of paternal involvement. However, among adolescents  $\geq 14$  years of age, PedsQL scores were significantly higher among those in the high tertile for DADS amount scores,  $F(2, 45) = 3.09, p < .05$ . Among this oldest age group, mean PedsQL total scores were 5.2 for the low tertile, 7.3 for the moderate tertile, and 10.7 for the high tertile. For both mother-reported and father-reported



**Figure 1.** Mean ( $\pm 1$  SEM) scores for treatment adherence expressed as the percentage of possible points earned on Disease-Specific Self-Management Profiles (SMP) for youth presented by age quartile and mothers' and fathers' Dads' Active Disease Support scale (DADS) amount score tertiles.



**Figure 2.** Mean ( $\pm 1$  SEM) total scores for children's quality of life expressed as total scores on the Pediatric Quality of Life Inventory (PedsQL) core scale presented by age quartile and mothers' and fathers' Dads' Active Disease Support scale (DADS) amount score tertiles.

DADS helpfulness scores, neither the main effects,  $F(2, 188) = 1.46, p = .30$  for mothers and  $F(2, 185) = 1.26, p = .49$  for fathers, nor the interaction with age,  $F(6, 184) = 1.29, p = .28$  for mothers and  $F(6, 181) = 1.04, p = .58$  for fathers, were statistically significant.

### **Association of DADS Scores with Youth's Health Outcomes**

Separate multivariate analyses of variance were completed with mother-reported and father-reported DADS amount and helpfulness score tertiles and age groups as the between-subjects variables and the subjective health status index and the frequencies of hospitalizations and of emergency room visits in the prior 6 months serving as the dependent variables. None of the multivariate main effects for DADS tertiles were statistically significant. The multivariate main effect for age groups was statistically significant,  $F(9, 30) = 3.41, p < .04$ , with post hoc analyses showing poorer health status with increasing age for the subjective health status index and for frequency of emergency room visits in the prior 6 months. However, the multivariate age group–DADS tertile interaction effect was not significant for either the DADS amount or helpfulness tertiles for either mothers or fathers, indicating that the deterioration in health status during adolescence was not influenced by the amount or helpfulness of paternal involvement in disease management.

### **Discussion**

This study examined the associations between a new measure of the amount and helpfulness of paternal involvement in the management of pediatric chronic diseases with measures of youth's treatment adherence, quality of life, and health outcomes. We hypothesized that greater quantity (DADS amount) and quality (DADS helpfulness) of paternal involvement in disease management would be associated with more favorable status among children with respect to treatment adherence, quality of life, subjective health status, and health care utilization. The results indicated some support for these hypotheses in that greater amount of paternal involvement was associated with more favorable treatment adherence and quality of life among children who were 14 years of age and older. But, there was no association between measures of paternal involvement and the measures of either health status or health care utilization. Mother-reported and father-reported ratings of the helpfulness of paternal involvement were also unrelated to the measured outcomes.

### **Treatment Adherence**

Scores on the SMP, expressed as optimal treatment adherence, were less favorable with increasing age of the child among those with DADS scores in the low and moderate ranges. However, among those with DADS scores in the high range, adherence scores were not lower among older, as compared with younger, age groups. Virtually the same effect was observed for both mother-reported and father-reported DADS scores. Paternal involvement in disease management appeared to retard the typical deterioration in treatment adherence that often begins in early adolescence. A deteriorating developmental trajectory around disease management may persist through early adulthood (Bryden, Peveler, Stein, Neil, Mayou, & Dunger, 2001; Kovacs, Iyengar, Mukerji, & Drash, 1996; Wysocki, Hough, Ward, & Green, 1992). Hence, the level of paternal involvement in disease management during late childhood and early adolescence might be expected to exert durable effects on subsequent treatment adherence during later adolescence and early adulthood.

### **Quality of Life**

Similar to the results obtained for treatment adherence, scores on the PedsQL quality of life instrument did not differ as function of degree of paternal involvement in disease management among the three younger age groups of children, but a different pattern emerged among adolescents. Based on both mothers' and fathers' DADS amount scores, among youth over 14 years of age, PedsQL total scores were significantly more favorable among youth with DADS scores in the high DADS tertile than among those in the moderate or low DADS tertiles. A noteworthy aspect of these data is that mean PedsQL total scores for older youth with both mothers' and fathers' DADS amount scores in the high range (mean PedsQL total scores = 11.3 and 10.7, respectively) were also significantly higher than those for all three of the other age groups, who had a mean PedsQL score of 6.44. There are several possible explanations for this curious finding. First, it may be a real effect indicating that quality of life for adolescents is more heavily dependent upon the quantity of paternal involvement than is true during earlier developmental periods. Alternatively, fathers may become involved after adolescents adapt successfully to disease management. The parallel findings indicating more favorable treatment adherence and quality of life among adolescents who enjoyed high paternal involvement suggest that these outcomes were interrelated in this study. Also, it is reasonable to suspect that better treatment adherence could yield better



quality of life by affecting health status and parent-adolescent relationships positively. Put another way, adolescents who are coping well with their medical conditions may be more receptive to inviting paternal involvement in that arena, thus creating even more opportunities for improved quality of life. These possible interpretations must be considered quite speculative until they are evaluated and confirmed by future research.

### **Health Status and Health Care Utilization**

Despite the positive associations between DADS scores and the measures of treatment adherence and quality of life presented above, there were no statistically significant effects of degree of paternal involvement on any of the health status indices that were collected (subjective health status, frequency of hospitalizations, and frequency of emergency room admissions). Multivariate analyses yielded no evidence that either the amount or helpfulness of paternal involvement in disease management buffered the age-related deterioration in health status. Thus, the protective effects of paternal involvement that were revealed with treatment adherence and quality of life were insufficient to yield corresponding effects on health outcomes. There are several possible mechanisms that could dilute possible associations among paternal involvement in disease management and youth's health outcomes. For example, there may be a bidirectional relationship between paternal involvement and children's outcomes. Fathers may become more involved in disease management both because it is going well or because it is going poorly. Conversely, there may be varied reasons why some fathers may become less involved in family management of the medical condition. Complex relationships such as these within the data could yield an overall estimate of no relationship among paternal involvement and children's outcomes when in fact there are several. Second, this study made no attempt to determine the duration or stability of each couple's current level of paternal involvement in disease management. Perhaps only prolonged, substantial paternal involvement would be sufficient to yield measurable effects on health status measures. Third, both hospitalizations and emergency room admissions in the prior 6 months were very uncommon, with no episodes of either type reported by most participating couples. Limited variability in these measures could prevent the demonstration of an association with paternal involvement in disease management. Finally, effects on children's health outcomes are necessarily indirect consequences of other processes such as treatment adherence, quantity, quality

and timeliness of health care, adequacy of nutrition, and so on. Although paternal involvement might be expected to influence all of these processes, effects on children's ultimate health status will be diluted by the extent to which these intermediary effects are limited in magnitude, duration, or consistency over time.

### **Conclusions**

The results of this study showed that the amount of paternal involvement in disease management was related to treatment adherence and quality of life, but that mothers' and fathers' ratings of the helpfulness of paternal involvement were consistently unrelated to the study outcomes. It is difficult to account for this pattern, especially in view of the results reported in our accompanying article (Gavin & Wysocki, in press) showing that DADS helpfulness scores were related to many dimensions of maternal, marital, and family functioning. This combination of findings suggests that helpfulness to mothers may be associated with favorable maternal and family adjustment, but that amount of paternal involvement may be a more important determinant of disease-specific psychological outcomes such as adolescents' treatment adherence and quality of life.

These results are somewhat consistent with predictions that could be derived from the Wallander et al. (1989) Risk and Resistance Model. If adherence and quality of life are viewed as indices of children's psychological adjustment to their medical conditions, the results of the study revealed that more paternal involvement in disease management was associated with better outcomes among adolescents in particular. Children in the younger age groups did not demonstrate similar associations between amount or helpfulness of paternal involvement with either treatment adherence or quality of life. It remains to be seen whether a longitudinal study of these same processes would affirm a causal relationship between paternal involvement and child outcomes or show that children who enjoyed more paternal involvement in earlier childhood would tend toward more favorable outcomes during adolescence. Together with our accompanying article on associations among paternal involvement and measures of maternal, marital, and family adjustment (Gavin & Wysocki, in press), we believe that our results affirm the merits of encouraging paternal involvement in the management of pediatric chronic diseases, particularly during adolescence.

Mothers' and fathers' reports of paternal involvement revealed very similar associations with the outcomes

measured in this study, suggesting that obtaining data from both may be redundant. Given that the DADS is a new measure and the research questions we have raised have been understudied, we would argue that it continues to be prudent to obtain the perspectives of both parents in similar future studies.

### Limitations of the Study

Several limitations of this study should be noted when interpreting the above results. Primary among these is the observation that this was a cross-sectional study that cannot demonstrate causal relationships or clarify the direction of effect, if any, when two variables are associated significantly with one another. Paternal involvement is just as likely to be a consequence of favorable adaptation to the disease among youth as it is to be a cause of that successful adaptation. Longitudinal studies that monitor change over time in paternal involvement with disease management along with repeated monitoring of child outcomes could clarify these competing interpretations.

Other limitations of the study relate to the limited confirmation of the psychometric properties of the SMP that served as measures of treatment adherence in this study. Further validation of each of these measures is needed with larger samples of children and adolescents with each medical condition. Also, the possible role of "mono-respondent bias" should be considered in evaluating the results. Although each parent completed the DADS independently, both contributed to the completion of other study measures. Evaluating the associations of parental reports of paternal involvement on measures obtained from children themselves or on objective measures of specific outcomes could circumvent this problem in future studies.

Future research should also seek to determine the precise mechanisms by which more paternal involvement is associated with more favorable youth outcomes. For example, some "direct" processes that may be worthy of exploration are parental monitoring of treatment tasks and frequency of delivery of positive and negative consequences for children's self-management behaviors. Similarly, "indirect" processes that may prove important are general effects of fathers' socially supportive behaviors toward mothers, enhancement of marital satisfaction, and facilitation of stress management and coping by individual parents. Another important set of research questions relates to the relationships among children with chronic medical conditions and noncustodial parents. Such children are likely to be at higher risk of

adjustment difficulties in general and around their medical conditions specifically, and so research on these families is needed.

Socioeconomic status and disease category were confounded in this sample, impeding the capacity to verify whether the overall findings were identical for the various diagnostic groups independent of socioeconomic status. The sample size was insufficient to enable controlling statistically for both disease category and socioeconomic status simultaneously, and so the possibility remains that the observed associations between paternal involvement and child outcomes may not hold equally for all disease types.

This study and the related reports (Gavin & Wysocki, in press; Wysocki & Gavin, 2004) lay the groundwork for additional investigations of paternal involvement in chronic disease management such as those outlined above. Research designed to explore these potential correlates of paternal involvement in chronic disease management would be particularly valuable in guiding the design and evaluation of family interventions targeting either the quantity or quality of that involvement.

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