

Brief Report: Psychosocial Functioning of Fathers as Primary Caregivers of Pediatric Oncology Patients

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Objective To evaluate the psychosocial functioning of fathers as primary caregivers of pediatric oncology patients. **Methods** Fathers who identified themselves as the primary medical caregivers were given a packet of questionnaires, including the Brief Symptom Inventory (BSI), the Impact of Event Scale (IES), the Impact on Family Scale (IFS), the Caregiver Strain Questionnaire (CGSQ), and the Parent Experience of Child Illness (PECI) scale, to complete and return by mail. The 23 fathers who returned the questionnaire packets were compared with 23 mothers who were matched on demographic variables. **Results** There were no differences between groups on self-report measures of distress or illness-related parenting stress. Descriptively, however, the majority of parents were above normative means on measures of psychological distress with a significantly greater proportion of fathers endorsing elevated levels of depression on the BSI. **Conclusion** Including fathers in pediatric psychosocial research is important and represents a growing trend in psycho-oncology.

Key words father adjustment; pediatric oncology; psychosocial functioning.

Historically, fathers have been underrepresented in research on pediatric patients and parenting (Phares, Lopez, Fields, Kamboukos, & Duhlig, 2005). However, the 20th century has brought important societal changes that have resulted in an increase in father involvement in the overall care of their children, particularly for intact family systems (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000). Subsequently, in recent years, the inclusion of fathers in child-oriented psychological research, and specifically pediatric psychology research, has become a topic of increased editorial attention, with numerous opinion pieces in journals such as *Pediatrics* (Pruett, 1998) and the *Journal of Pediatric Psychology* (Seagull, 2000) calling for the inclusion of fathers as an emerging and vital need in the field. Furthermore, during a recent conference on pediatric psychology, the inclusion of fathers in pediatric research was described as a critical need in the field (Brown, 2006).

Findings from recent empirical investigations involving fathers revealed that paternal involvement in pediatric illness management is beneficial across many areas, including medication/treatment adherence and quality of

life (Wysocki & Gavin, 2006). Specifically, higher levels of mother-reported father involvement were associated with better psychosocial outcomes, including maternal, marital, and family functioning (Gavin & Wysocki, 2006).

A comprehensive review of the literature revealed that in the last decade, 23 studies were completed with parents of childhood cancer patients that compared fathers and mothers. The large majority of these studies used mother–father pairs as participants and found that fathers’ reports of adjustment were generally comparable to those of mothers on most psychosocial measures such as depression, anxiety, and symptoms of post-traumatic stress (Kazak et al., 2004, 2005; Sloper, 2000). However, of importance to the current study, only one of these studies identified a parent as the primary medical caregiver (Frank, Brown, Blount, & Bunke, 2001). This distinction—between fathers serving as the *primary medical* caregivers and fathers serving as nonprimary medical caregivers—is one which may potentially mask important differences in their experiences. Indeed, fathers who function in the role of primary medical caregiver are more proximal to the medical experience (e.g., scheduling and attending clinic appointments,

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involvement during hospital stays, and managing medication regimens) than fathers who do not serve as primary caregivers. As such, they may be more likely to experience elevated levels of distress.

A recent study examined the psychological functioning of fathers caring for children infected with HIV (Wiener, Vasquez, & Battles, 2001). As compared to a normative sample, the fathers of these children experienced significantly more child-related stress and significantly higher rates of distress. Furthermore, one-third of the sample endorsed rates of distress indicative of the need for professional intervention. Studies such as these underscore the importance of examining the impact of the medical experience on the psychological functioning of fathers serving as primary caregivers, rather than generalizing from studies of mothers as primary caregivers or fathers who do not serve in the primary caregiver role.

Given the obvious benefits of father inclusion in a child's medical management, it is imperative that both empirical investigations as well as interventions focus on the entire family—including the child, the mother, and the father, especially when the father is considered the primary medical caregiver of the child. The aim of the current study was to assess the psychological functioning of fathers who served as the primary medical caregivers of their children with cancer. These fathers were compared to a matched group of mothers who also served as the primary medical caregivers of their children with cancer.

Methods

Procedures

Parents who had participated in a larger ongoing protocol examining psychosocial functioning of primary medical caregivers of pediatric patients with cancer were included in this study. Participants were approached by the project coordinator at one of their child's regularly scheduled oncology clinic appointments. After giving their consent using Institutional Review Board-approved methods, parents were asked to provide demographic information about themselves, their child, and their child's illness history. All illness-related information was later verified by chart review. Consenting parents were asked to take home a packet of measures to complete and return by mail 1 week later using an included addressed and stamped envelope.

A total of 177 parents were consented as part of the larger sample. All English-speaking parents of pediatric cancer patients receiving treatment in the Divisions of Pediatric Neuro-Oncology and Pediatric Hematology/Oncology were eligible for participation. Consent was

obtained from all parents approached; however, completed packets were returned by only 118 parents (66.7%), with 23 of these (19.5%) being fathers.

Participants

Thirty-three fathers who identified themselves as the primary medical caregiver—defined as the parent primarily responsible for the child's care, within and outside the medical context—provided initial consent for the study. Twenty-three (69.6%) of those returned questionnaire packets. These fathers were subsequently matched to a sample of mothers who were part of the larger sample on a one-to-one basis. Participants were matched on race, age (within 5 years), marital status (married/living with partner or unmarried/no partner in the home), child age (within 2 years), and level of education (high school diploma or less, some college, college/graduate degree). Matched controls meeting all of the above criteria were found for 21 of the 23 fathers. For the remaining two fathers, matching mothers were found for all parameters except level of education. Additionally, if more than one possible match was found for a father, a match was chosen at random from among the choices.

Of note, 10 fathers (30.4%) consented to the study but did not return questionnaire packets. Comparisons using *t*-tests and chi-square analyses were made when statistically valid between fathers who returned study measures and those who did not. No significant differences were found between parent (age) or child (gender, age, treatment status, time since diagnosis, and age since diagnosis) variables among those who returned packets and those who did not; however, comparisons between the fathers' race and education levels were not computed because cell sizes fell below five.

Demographic characteristics of the sample are listed in Table I. Preliminary analyses were conducted to verify that no significant demographic differences were present between mothers and fathers. As expected, *t*-tests and chi-square tests verified that parent age, race, education, and child age were similar between groups. Moreover, no significant differences were found between groups for unmatched characteristics including child gender, diagnosis, age at diagnosis, treatment status, or time since diagnosis.

Measures

Brief Symptom Inventory

The Brief Symptom Inventory (BSI; Derogatis & Spencer, 1982) is a 53-item self-report measure designed to reflect a broad array of psychological symptom patterns. The Depression, Anxiety, Somatization, and Global Symptom

Table I. Demographic Information by Group

	Fathers		Mothers	
	<i>M</i> ± <i>SD</i>	<i>N</i> (%)	<i>M</i> ± <i>SD</i>	<i>N</i> (%)
Parents				
Age	40.1 ± 5.7		39.5 ± 5.6	
Race				
Caucasian		20 (87.0)		20 (87.0)
African-American		3 (13.0)		3 (13.0)
Education				
High school		5 (21.7)		5 (21.7)
Some college		8 (34.8)		8 (34.8)
College graduate and above		10 (43.5)		10 (43.5)
Marital status				
Married		18 (78.3)		18 (78.3)
Not married		5 (21.7)		5 (21.7)
Child				
Age	9.5 ± 5.7		9.6 ± 5.4	
Gender				
Male		9 (39.1)		10 (43.5)
Female		14 (60.9)		13 (56.5)
Race				
Caucasian		20 (87.0)		20 (87.0)
African-American		3 (13.0)		3 (13.0)
Age at diagnosis	7.7 ± 5.9		6.6 ± 5.5	
Months since diagnosis	21.4 ± 36.0		34.9 ± 41.7	
Diagnosis				
Brain tumor		17 (73.9)		19 (82.6)
NonCNS cancer		6 (26.1)		4 (17.4)
Treatment Status				
On treatment		13 (56.5)		10 (43.5)
Off treatment		10 (43.5)		13 (56.5)

No significant differences between mothers and fathers on any demographic variable.

Index (GSI) subscales were used for this study. For each scale, scores were transformed into *T*-scores ($M = 50$, $SD = 10$). The BSI has demonstrated good test-retest reliability and construct validity (Derogatis, 1993), and has been used in research with chronic illness populations (Thompson & Gustafson, 1996), though with some reservations (Gerhardt et al., 2003).

Impact of Event Scale

The Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979) is a 15-item questionnaire rated on a 4-point scale for frequency of post-traumatic stress symptoms during the previous week. The IES has high internal consistency and test-retest reliability (Zilberg, Weiss, & Horowitz, 1982) and has been used with childhood cancer survivors, as well as children with other medical conditions (Kazak et al., 1997, 1999). The Total scale was used in this study.

Parent Experience of Child Illness

The Parent Experience of Child Illness (PECI; Bonner, Hardy, Guill, McLaughlin, Schweitzer, and Carter 2006) is a 25-item parent-report measure of a parent's illness-specific adjustment to their child's serious or chronic illness. Initially validated in a study of 149 parents of children with brain tumors, an initial factor structure yielded four factors: Guilt and Worry, Emotional Resources, Unresolved Sorrow and Anger, and Long-term Uncertainty. Internal consistency for the four scales is adequate, ranging from .72 to .89 (Bonner et al., 2006).

Impact on Family Scale

The Impact on Family Scale (IFS; Stein & Jessop, 2003; Stein & Reissman, 1980) is a 33-item self-report questionnaire that is designed to assess how family functioning is influenced by a child's illness. The Total scale score (internal consistency reliability = .88; Stein & Reissman, 1980) and the Coping Subscale were used for this study. This measure demonstrates good psychometric properties as described by Stein & Jessop (2003).

Caregiver Strain Questionnaire

Developed for use in the Fort Bragg Evaluation Project (Bickman et al., 1995), the Caregiver Strain Questionnaire (CGSQ; Brannan, Heflinger, & Bickman, 1997) is a 21-item self-report measure that assesses adults' perception of difficulties associated with their parenting role. Factor analysis derived three subscales: Objective Burden, Externalized Subjective Burden, and Internalized Subjective Burden, all of which were used in the current study. Internal consistency reliability ranged from .74 to .93; evidence for construct validity with other measures of family and parental functioning has also been demonstrated (Brannan et al., 1997).

Results

A series of paired *t*-tests were conducted to compare psychological functioning between parent groups; the Bonferroni correction was employed to control for familywise error rate given the large number of comparisons performed. Across measures, there were no significant differences between mothers' and fathers' reported psychological distress (see Table II). However, both genders evidenced considerable distress when compared to the normative samples for the questionnaire measures. On the BSI, the number of parents obtaining a *T*-score above 63, cited by Derogatis (1993) as a clinically meaningful cutoff, was examined. Across the Depression,

Table II. Questionnaire Means and Standard Deviations by Group

	Fathers <i>M</i> ± <i>SD</i>	Mothers <i>M</i> ± <i>SD</i>
BSI		
Depression	62.6 ± 11.0	58.6 ± 7.6
Anxiety	60.1 ± 13.3	59.3 ± 8.3
Somatization	55.6 ± 12.8	56.3 ± 10.1
GSI	60.8 ± 12.8	60.0 ± 7.9
IES		
Total	21.7 ± 13.5	27.1 ± 13.4
PECI		
Guilt & Worry	1.80 ± .66	1.86 ± .66
Unresolved Sorrow & Anger	1.58 ± .81	1.59 ± .58
Long-term Uncertainty	2.00 ± .72	2.00 ± .73
Emotional Resources	2.58 ± .62	2.72 ± .53
IFS		
Coping	7.8 ± 2.3	7.4 ± 1.5
Total	45.1 ± 10.7	46.7 ± 8.6
CGSQ		
Objective Burden	2.45 ± .81	2.55 ± .87
Externalized Subjective Burden	1.95 ± .42	2.03 ± .21
Internalized Subjective Burden	3.24 ± .98	3.10 ± .80

BSI, Brief Symptom Inventory; IES, Impact of Event Scale; PEGI, Parent Experience of Child Illness; IFS, Impact on Family Scale; CGSQ, Caregiver Strain Questionnaire.

The scores for the BSI are *T*-scores with *M* = 50 and *SD* = 10. All others scores are means and standard deviations for the sample.

No significant differences between mothers and fathers on any questionnaire measure.

Anxiety, Somatization, and GSI scales, a sizable proportion of mothers and fathers showed elevated levels of distress. Specifically, nearly half of the fathers ($n = 11$) and a third of mothers ($n = 8$) obtained a GSI above 63. With regard to anxiety, parents also exhibited relatively high levels of distress, with half of mothers ($n = 11$) and 39.1% of fathers ($n = 9$) having *T*-scores of 63 or above. Over one-third of fathers ($n = 8$, 34.8%) and about a quarter of mothers ($n = 5$, 21.7%) endorsed Somatization symptoms greater than 63. Finally, although a number of parents showed elevations on the depression scale, a trend for a significantly greater proportion of fathers (56.5%, $n = 13$) than mothers (26.0%, $n = 6$) scored a *T*-score of 63 or above ($\chi^2 = 5.02$, $p = .02$).

On the IES, the majority of both genders fell within the “high” symptom category for the measure. Specifically, 13 fathers (56.5%) and 15 mothers (68.2%) scored 19 or above on the IES total symptom scale. However, there were again no significant differences between mothers and fathers on this measure.

On measures of parenting stress (i.e., PEGI, IFS, CGSQ), paired *t*-tests were again performed to assess differences between parent groups. As with measures of general psychological distress, there were

no significant differences between mothers’ and fathers’ reports of illness-related parenting stress. Moreover, in contrast to the high levels of distress manifested by many parents on the self-report measures, mothers’ and fathers’ ratings of parenting stress were more consistent with standardization samples of the measures used.

Given the lack of significant differences between gender groups, additional exploratory analyses were conducted to determine whether other parent demographic factors were more strongly associated with distress than gender. As such, differences were assessed on all measures for parent age, level of education, and marital status. There were no associations between parent age or education and the outcome measures; however, parent marital status significantly predicted distress on some measures. Regardless of gender, unmarried parents experienced more guilt ($t = -1.83$, $p = .07$), more anxiety ($t = -1.77$, $p = .08$), more somatization ($t = -2.89$, $p < .01$), more global symptom severity ($t = -2.01$, $p = .05$), and greater internalized subjective burden ($t = -1.84$, $p = .07$). While small cell sizes did not allow for statistical assessment of an interaction between marital status and gender, examination of the data suggests that single fathers may experience more severe levels of distress than either single mothers, or married fathers or mothers. For example, on the BSI Depression scale, four out of five single fathers evidenced scores in the clinical range, whereas only one of five single mothers did so.

Finally, differences were assessed across diagnosis given that the majority of the sample was a parent to a child with a brain tumor, a group that may be especially vulnerable to distress. However, no differences were found between parents of brain tumor patients and parents of general oncology patients for any of the measures.

Discussion

In keeping with the recent appeal to include fathers in pediatric psychology research, the current study examined the psychosocial functioning of a small sample of fathers who identified themselves as taking the *primary* role in managing their child’s health-related care. These fathers were compared to a matched sample of mothers who had also identified themselves as the primary medical caregiver of their ill child.

Consistent with extant literature, there were no differences between fathers and mothers across most measures of psychosocial functioning. However, when

results were examined and compared descriptively, both fathers and mothers elicited levels of self-reported psychological distress that were above normative means. In addition, a significantly greater proportion of fathers than mothers reported elevated rates of depressive symptoms. A qualitative examination of the data suggested that unmarried fathers may be particularly likely to report symptoms of depression. As such, future studies should include a broader assessment of personal and environmental stressors, coping styles, and social support (Noll et al., 1995).

This study has several limitations, including a relatively small sample size, which would reliably detect only very large differences between mothers and fathers who are the primary medical caregivers of children with cancer. The study also relied on a convenience sample of parents. Even though our response rate was comparable to other studies relying on survey methods, it is possible that fathers who did not respond differed in nonrandom ways from those who did. Specifically, it may be that fathers who responded to the questionnaires were either higher functioning than those who did not, or that respondents were those whose interest in participation was prompted by their ongoing distress associated with their children's cancer experience.

Additionally, the use of the BSI is another limitation, especially considering the recent concerns that have been raised about its use with parents of children with chronic illnesses (Gerhardt et al., 2003). However, it is still considered a standard measure of psychosocial health for adults, and continues to be used in this capacity, even with caregivers of childhood cancer patients (Robinson, Gerhardt, Vannatta, & Noll, in press). Finally, because of the unique stressors experienced by families of children diagnosed with a brain tumor, our sample, which is heavily comprised of parents of brain tumor patients, may be somewhat biased. Although there were no statistically significant differences between the brain tumor and nonbrain tumor groups, the number of parents in the nonbrain tumor group was too small to make any concrete conclusions regarding a lack of differences between these populations. As such, the findings may not be generalizable to parents of children with other types of cancers.

Overall, the results of this study reiterate the need for conceptualizing pediatric cancer—and other chronic and serious illnesses that affect children—as a “family disease” (Chesler & Barbarin, 1987) with close attention paid to all members of the social ecology (Kazak, 2005).

Indeed, routine inclusion of fathers, particularly those who identify themselves as primary medical caregivers, will provide important data for understanding their unique needs as parents of ill children as well as the resources they bring to the situation. Our data indicated that unmarried fathers, in particular, may warrant further attention in this regard. Moreover, future studies should also compare these fathers with those who do not assume the primary medical caregiving role in the family to determine if there are differences in psychosocial adjustment. This information would allow interventions to be tailored to the unique needs of the family environment.

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