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## ABSTRACT

Studies of parents of children treated for cancer have rarely included adequate samples of fathers or couples. Further, bereaved parents have been over-represented as compared to parents of cancer survivors. This study investigated the personal and interpersonal effects of having a child treated for cancer on 124 parents. Twenty-seven married couples were bereaved and 33 married couples were nonbereaved. Four bereaved parents without spouses were also included. All survivors had been off-treatment for at least 6 months and the average time since diagnosis was 6 years. Effects at the personal level-psychological distress-were assessed by self-report on one global scale and 7 subscales of the Brief Symptom Inventory (BSI). Effects at the interpersonal level-marital satisfaction-were assessed by self-report on the summary scale and 2 factors of the Marital Adjustment Test. Mothers and fathers reported higher levels of psychological distress than nonpatient norms, but lower levels than outpatient psychiatric norms. Fathers reported lower levels of marital satisfaction than nonreferred male norms; mothers did not differ from norms on marital satisfaction. Matched pairs t-tests on 60 couples demonstrated no differences between mothers and fathers in terms of levels of psychological distress and marital satisfaction. Bereaved and nonbereaved mothers did not differ on reported levels of psychological distress after controlling for the effects of time since diagnosis. This time effect appeared to be more salient for mothers, with mothers of more recently diagnosed children reporting higher levels of distress. Bereaved fathers did report higher levels of psychological distress on several BSI subscales than did nonbereaved fathers; no effect of time since diagnosis was observed for fathers. After a median split into high and low on the distress dimension, bereaved mothers reporting higher psychological distress also reported lower satisfaction with their marriages. Fathers reporting higher levels of psychological distress also reported lower marital satisfaction, but this was true of both bereaved and nonbereaved fathers. The results reveal some areas of similarity in outcome for bereaved and nonbereaved parents and for mothers and fathers of children treated for cancer. There are suggestions, however, of differential processes for mothers

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Individual and Marital Adjustment Among Bereaved and  
Nonbereaved Parents of Children Treated for Cancer

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## ABSTRACT

Studies of parents of children treated for cancer have rarely included adequate samples of fathers or couples. Further, bereaved parents have been over-represented as compared to parents of cancer survivors. This study investigated the personal and interpersonal effects of having a child treated for cancer on 124 parents. Twenty-seven married couples were bereaved and 33 married couples were nonbereaved. Four bereaved parents without spouses were also included. All survivors had been off-treatment for at least 6 months and the average time since diagnosis was 6 years. Effects at the personal level-psychological distress-were assessed by self-report on one global scale and 7 subscales of the *Brief Symptom Inventory*. Effects at the interpersonal level-marital satisfaction-were assessed by self-report on the summary scale and 2 factors of the *Marital Adjustment Test*. Mothers and fathers reported higher levels of psychological distress than nonpatient norms, but lower levels than outpatient psychiatric norms. Fathers reported lower levels of marital satisfaction than nonreferred male norms; mothers did not differ from norms on marital satisfaction. Matched pairs t-tests on 60 couples demonstrated no differences between mothers and fathers in terms of levels of psychological distress and marital satisfaction. Bereaved and nonbereaved mothers did not differ on reported levels of psychological distress after controlling for the effects of time since diagnosis. This time effect appeared to be more salient for mothers, with mothers of more recently diagnosed children reporting higher levels of distress. Bereaved fathers did report higher levels of psychological distress on several *BSI* subscales than did nonbereaved fathers; no effect of time since diagnosis was observed for fathers. After a median split into high and low on the distress dimension, bereaved mothers reporting higher psychological distress also reported lower satisfaction with their marriages. Fathers reporting higher levels of psychological distress also reported lower marital satisfaction, but this was true of both bereaved and nonbereaved fathers. The results reveal some areas of similarity in outcome for bereaved and nonbereaved parents and for mothers and fathers of children treated for cancer. There are suggestions, however, of differential processes for mothers and fathers in terms of the effects of time since diagnosis, treatment outcome, and personal distress on satisfaction with the marital relationship. The results are suggestive of the complexities of parental coping with childhood cancer and the need for greater specificity and continued study.

## **BACKGROUND**

Studies of parents of children treated for cancer were conducted primarily on samples of bereaved parents for many years. With improved antineoplastic treatment and survival, and a resultant shift to viewing childhood cancer within a chronic illness model, questions as to the long-term effects of childhood cancer on parents have surfaced. Studies with parents of survivors are few however, and rarely have they employed standardized measurement instruments.

Studies of parents of children with a variety of chronic or life-threatening illnesses (including cancer) have focused primarily on mothers, with surprisingly little attention being given to fathers, the marital relationship of the parents, or overall family functioning. This lack of empirical evidence has not prevented some from concluding that mothers of chronically ill children experience greater distress than do fathers. Comparison studies are clearly needed.

When control groups have been used, investigators have tended to look to "normal" parents (i.e.; parents whose children do not have a chronic illness). Initially, this may have been useful in a descriptive sense, but it has also served to support a more pathological perception of these parents than may be warranted. What is needed currently is more systematic research aimed at exploring the complexities that are involved in parental coping with a chronic, life-threatening childhood illness.

Typically, parents whose children have died from cancer and parents of cancer survivors have not been compared. This may be due, in part, to assumptions and expectations for bereaved parents to experience greater distress. While intuitively appealing, this assumption has not been adequately tested.

## **PURPOSE OF THE STUDY**

The purpose of the study was to investigate the degree of psychological distress and marital satisfaction among parents of children treated for cancer. Further, we sought to compare the psychological distress and marital satisfaction of mothers of children treated for cancer with that of fathers of children treated for cancer. Lastly, we proposed comparing the degree of psychological distress and marital satisfaction of bereaved parents with that of parents of long-term survivors of cancer.

## **RESEARCH QUESTIONS**

1. Do parents of children treated for cancer report (a) elevated levels of psychological distress or (b) lower levels of marital satisfaction as compared with a normative sample?
2. Do mothers and fathers differ on the degree of reported (a) psychological distress or (b) marital satisfaction following the treatment of a child for cancer?

3. Do bereaved parents report (a) higher levels of psychological distress or (b) lower levels of marital satisfaction as compared to parents of cancer survivors ?

## **PARTICIPANTS**

Subjects were 124 parents of children treated for cancer. Twenty-seven married couples were bereaved parents (N=54) and 33 married couples were parents of a cancer survivor (N=66). Two bereaved mothers were single parents (divorced prior to the child's diagnosis with cancer) and one bereaved father and one bereaved mother from two different married couples did not complete the questionnaires.

Eligibility Criteria. Each parent must have been present in the home at the time of the cancer diagnosis and throughout the treatment period. The child's cancer diagnosis was less than 10 years ago and the time from diagnosis to the end of treatment (or death) was at least 6 months. The child with cancer was no longer receiving active treatment. There was at least one healthy sibling in each family.

The results reported represent preliminary analyses from a larger study designed to explore the effects of family functioning characteristics on the adjustment outcome of siblings and parents following the treatment of a child for cancer.

## **INSTRUMENTS**

BSI - Brief Symptom Inventory - self-report (Derogatis & Spencer, 1982) is a 63-item multidimensional standardized inventory which assesses current point-in-time psychological symptom status. It is the short form of the *SCL-90*. Higher scores indicate higher levels of symptomatology. The *BSI* includes 9 subscales and 3 summary scales. Seven subscales were of interest with the present sample (based on the literature):

- |  |                                  |
|--|----------------------------------|
| -somatization ( <i>SOM</i> )             | -anxiety ( <i>ANX</i> )          |
| -obsessive-compulsive ( <i>OC</i> )      | -hostility ( <i>HOS</i> )        |
| -interpersonal sensitivity ( <i>IS</i> ) | -paranoid ideation ( <i>PI</i> ) |
| -depression ( <i>DEP</i> ).              |                                  |

One summary scale was also used:  
-Global Severity Index (*GSI*).

MAT - Marital Adjustment Test - self-report (Kimmel & van der Veen, 1974) is a 23-item standardized measure designed to assess levels of marital satisfaction and accommodation of spouses to one another. Higher scores indicate higher levels of marital satisfaction. The *MAT* includes 2 factors and 1 summary score. Two factors were examined:

- |                               |                                      |
|-------------------------------|--------------------------------------|
| -compatibility ( <i>COM</i> ) | -sexual congeniality ( <i>SEX</i> ). |
|-------------------------------|--------------------------------------|

These 2 factors are scored differently for females and males; therefore scores across gender on *COM* and *SEX* are not comparable.

One summary score was also used:

- Total Marital Satisfaction (*TMS*).

The summary scale is scored the same for females and males.

## PROCEDURES

### Subject Identification

The mailing list of a local parent fund-raising group was utilized to contact potential subject families. Active group participation was *not* a prerequisite for inclusion on the mailing list, thereby decreasing concerns of self-selection.

### Data Collection

Assessment interviews were conducted by the investigator and 2 trained research assistants in the homes of the parents. Informed consent was obtained from each participant. A semi-structured interview was used to collect demographic and treatment data. Parents then completed the self-report measures. Debriefing and emotional reactions were assessed and referrals to counseling services were provided.

## ANALYSES

### 1. t-tests comparing parents of children treated for cancer with standardized norms for BSI and MAT:

Independent variable - *group* (parents vs. normative samples for *BSI* and *MAT*)  
Dependent variables - (a) *GSI* score, (b) *TMS* score.

### 2. t-test comparing parents by gender:

Matched pairs t-tests were used to compare the (a) degree of overall psychological distress among mothers and fathers on *BSI* summary scale (*GSI*) and (b) the degree of overall marital satisfaction among mothers and fathers on the *MAT* summary score (*TMS*).

Married mothers and fathers were paired and assessed for differences given the non-independence of a married couples sample.

Independent variable - *gender*.  
Dependent variable - (a) *GSI* score, (b) *TMS* score.

### 3. MANOVAs comparing parents by status:

One-way MANOVAs were used to compare the degree of psychological distress between bereaved and nonbereaved mothers and fathers.

MANOVAs were run separately on mothers and fathers given the non-independence of the sample.

A covariate (*time since diagnosis*) was entered first given that the bereaved and



nonbereaved samples differed significantly on this variable.

Factor- status (bereaved vs. nonbereaved).

Multivariate dependent variables - 7 subscales of the *BSI* (*SOM, OC, IS, DEP, ANX, HOS, PI*).

#### 4. MANOVAs comparing parents by status and level of psychological distress:

Two-way MANOVAs (2 x 2) were used to compare the degree of marital satisfaction among bereaved and nonbereaved mothers and fathers who reported high vs. low levels of psychological distress.

MANOVAs were run separately for mothers and fathers given the non-independence of the sample and the lack of gender comparability on the 2 *MAT* factors.

Median splits were done on the *GSI* summary scale of the *BSI*. Parents were then coded as *high* or *low* on the factor *distress*.

A covariate (*time since diagnosis*) was entered first given that the bereaved and nonbereaved samples differed significantly on this variable.

Factors - *status* (bereaved and nonbereaved) and *distress* (high and low).

Multivariate dependent variables - 2 factors and summary score of the *MAT* (*COM, SEX, TMS*).

The .05 probability level was adopted for reporting significance for all analyses.

## RESULTS

### t-tests

Parents of children treated for cancer reported levels of psychological distress on the *BSI-GSI* summary scale and 6 of 7 *BSI* subscales (*OC, IS, DEP, ANX, HOS, PI*) which were significantly **higher** than those reported by a nonpatient normative sample. (Table 1).

Parents of children treated for cancer reported levels of psychological distress on the *BSI-GSI* summary scale and all 7 *BSI* subscales which were significantly **lower** than those reported by an outpatient psychiatric normative sample.

Mothers of children treated for cancer reported levels of marital satisfaction on the *MAT-TMS* summary scale that **did not differ** significantly from those reported by a nonreferred female normative sample. (Table 1).

Fathers of children treated for cancer reported levels of marital satisfaction on the *MAT-TMS* scale that were significantly **lower** than those reported by a nonreferred male



normative sample. (Table 1).

Matched pairs t-tests revealed that mothers and fathers of children treated for cancer did not differ significantly from one another on reported levels of psychological distress as measured by the *BSI-GSI* summary scale nor on reported levels of marital satisfaction as measured by the *MAT-TMS* summary scale. (Table 2).

## MANOVAs

Mothers of children more recently diagnosed with cancer reported significantly higher levels of psychological distress on 5 of 7 *BSI* subscales (*IS, DEP, ANX, HOS, PI*) than did mothers of children diagnosed less recently. (Table 3).

Mothers of deceased children did not differ significantly from mothers of children who had survived cancer on reported levels of psychological distress as measured by 7 subscales of the *BSI* (*SOM, OC, IS, DEP, ANX, HOS, PI*) after controlling for the effect of *time since diagnosis*. (Table 3).

Fathers of deceased children reported significantly higher levels of psychological distress on 3 of 7 *BSI* subscales (*OC, DEP, PI*) than did fathers of children who had survived cancer. There was no significant effect of *time since diagnosis* for fathers. (Table 4).

For mothers of children treated for cancer, no main effect was found for *status* (bereaved vs. nonbereaved) nor for level of reported psychological *distress* on reported levels of marital satisfaction. (Table 5).

An interaction effect was found, with bereaved mothers reporting higher levels of distress on the *BSI-GSI* reported significantly lower levels of marital satisfaction on the *MAT* subscale *Sexual Congeniality* and the summary scale, *MAT-TMS* than did bereaved mothers reporting lower distress and nonbereaved mothers reporting both higher and lower levels of distress. (Table 5).

For fathers of children treated for cancer, only a main effect for level of psychological *distress* was found. Fathers reporting higher levels of distress on the *BSI-GSI* reported significantly lower levels of marital satisfaction on both *MAT* subscales (*COM, SEX*) and on the summary scale (*TMS*) than did fathers reporting lower levels of psychological distress. This was true both for bereaved and nonbereaved fathers. (Table 6).

## CONCLUSIONS

Consistent with other studies, parents of children treated for cancer reported significantly higher levels of psychological distress in the areas of depression, anxiety, hostility, interpersonal sensitivity, obsessive-compulsive disorder, and paranoid ideation than did a nonpatient normative sample.

Their scores, however, were significantly lower than an outpatient psychiatric normative

sample. Further, the mean scores for the parent sample did not exceed the clinical cut-off (T score > 63) of the *BSI*. At (on average) 6 years after diagnosis, these parents do appear to be experiencing greater distress, but the clinical significance of this elevation is unclear.

Fathers of children treated for cancer also reported lower levels of marital satisfaction than did a nonreferred normative group; a lower level of marital satisfaction was not found among mothers.

Mothers and fathers of children treated for cancer reported similar levels of psychological distress and marital satisfaction, in contrast to previous studies which have suggested that mothers of ill children are affected more negatively than are fathers.

The lack of a main effect for *status* for mothers suggests that bereaved and nonbereaved mothers of children treated for cancer do not differ in terms of the degree of subsequent psychological distress. For mothers, the length of time since diagnosis appears to be a more salient factor.

For fathers, bereavement was associated with more psychological distress in the areas of obsessive-compulsive disorder, depression, and paranoid ideation. No time effect was found for fathers.

It may be that mothers of children who have survived cancer remain distressed in part due to fear of relapse, concerns over long-term toxic effects of the treatment, residual disabilities, etc. Fathers may be experiencing less distress in this realm or have a more optimistic appraisal of their child's future. These potential correlates remain to be investigated.

Bereaved mothers who are experiencing higher levels of psychological distress appear to be at higher risk for less satisfaction with their marriages. Perhaps, the loss of the relationship with the child acts to heighten the inadequacies or disappointments she perceives in her other significant relationships.

Interestingly, more highly distressed nonbereaved mothers did not report lower marital satisfaction. While the explanation is unclear, it may be that for these mothers, a continued focus on the survivor and maintenance of her role as caregiver to a chronically ill child act to ameliorate or buffer potential dissatisfaction with the marital relationship.

More highly distressed fathers reported lower marital satisfaction, whether bereaved or nonbereaved. It is unclear if this is specific to fathers of children treated for cancer or is a process more broadly evident in the general population.

These results suggest that:

- (1) further exploration of the effect of childhood cancer on parents include adequate paternal and/or parental couple samples;
- (2) assumptions about the long-term effects of childhood cancer on parents may be too simplistic, especially in regards to expectations commonly held that bereaved parents will be more distressed than parents of cancer survivors. It is more likely that the *quality* of

the distress of bereaved and nonbereaved parents is what differs. These potential qualitative differences demand further investigation;

(3) while mothers and fathers of children treated for cancer appear to experience similar levels of overall psychological distress and marital satisfaction, several factors may be contributing to differential processes in regard to the more specific effects of time since diagnosis, outcome of treatment, and perception of the marital relationship on subsequent parental functioning;

(4) further study of factors such as gender role expectations, presence and accessibility of adequate social support, opportunities for employment, family functioning characteristics, and continuing concerns of parents of long-term survivors is warranted in order to begin to unravel the complexities in parental coping with childhood cancer that have been suggested by these results.

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**Table 1 - t-test: BSI and MAT Mean Raw Scores of Parents of Children Treated for Cancer Compared with Normative Samples.**

<u>BSI-Dependent Measure</u>	<u>Parent Sample N=124</u>	<u>Nonpatient Norms N=719</u>	<u>t</u>
BSI - Somatization Mean SD	0.32 0.54	0.29 0.40	0.5915 NS
BSI - Obsessive-Compulsive Mean SD	0.83 0.71	0.43 0.48	6.0368 ***
BSI - Interpersonal Sensitivity Mean SD	0.54 0.63	0.32 0.48	3.7081 ***
BSI - Depression Mean SD	0.51 0.66	0.28 0.46	3.7289 ***
BSI - Anxiety Mean SD	0.51 0.53	0.35 0.45	3.1683 **
BSI - Hostility Mean SD	0.56 0.65	0.35 0.42	3.4711 ***
BSI - Paranoid Ideation Mean SD	0.53 0.56	0.34 0.45	3.5829 ***
BSI - Global Severity Index Mean SD	0.50 0.48	0.30 0.31	4.4893 ***
<u>MAT-Dependent Measure</u>	<u>Parent Sample</u>	<u>Nonreferred Norms</u>	<u>t</u>
MAT - Total Marital Satisfaction-Mothers Mean SD N	106.43 16.27 61	108.40 16.32 149	-0.796 NS
MAT - Total Marital Satisfaction-Fathers Mean SD N	104.51 15.97 61	110.22 16.28 157	-2.7081 **

\*\* p<.01

\*\*\* p<.001



<u>Dependent Variables</u>	<u>Mothers</u>	<u>Fathers</u>	<u>t</u>
BSI-Global Severity Index			
Mean	55.117	56.500	t = -0.87
SD	9.803	11.434	df= 59
N	60	60	p = .387 NS
MAT-Total Marital Satisfaction			
Mean	106.650	104.883	t = 0.91
SD	16.310	15.836	df= 59
N	60	60	p = .366 NS

**Table 3 - One-way MANOVA: Brief Symptom Inventory Subscales by Status - Mothers**

MANOVA

Covariate - *time since diagnosis*

Wilks $\lambda$	Approximate $F$	df	Significance
0.6936	3.4074	7,54	$p=.004$

Univariate Regression Analyses

Dependent Variables - *BSI subscales*

Subscale	Adjusted $R^2$	Beta	df	$F$	Signif.
Somatization	.03385	-.2229	1,60	3.1371	$p=.082$ NS
Obsessive-compulsive	.01087	-.1646	1,60	1.6701	$p=.201$ NS
Interpersonal Sensitivity	.14901	-.4037	1,60	11.6809	$p=.001$
Depression	.05702	-.2692	1,60	4.6884	$p=.034$
Anxiety	.07621	-.3023	1,60	6.0323	$p=.017$
Hostility	.20817	-.4703	1,60	17.0371	$p=.000$
Paranoid Ideation	.07995	-.3083	1,60	6.3009	$p=.015$

MANOVA

Factor - *status*

Wilks $\lambda$	Approximate $F$	df	Significance
0.8057	1.8607	7,54	$p=.094$ NS

**Table 4 - One-way MANOVA: Brief Symptom Inventory Subscales by Status - Fathers**

MANOVA

Covariate - time since diagnosis

Wilks $\lambda$	Approximate $F$	df	Significance
0.86782	1.1315	7,52	$p=.358$ NS

MANOVA

Factor - status

Wilks $\lambda$	Approximate $F$	df	Significance
0.73236	2.7148	7,52	$p=.018$

Univariate ANOVA

Dependent Variables - BSI subscales

Subscale	Source	SS	MS	df	$F$	Signif.
Somatization	between	41.6145	41.6145	1	0.4086	$p=.525$ NS
	within	5907.7766	101.8582	58		
Obsessive-compulsive	between	697.5888	697.5888	1	5.8063	$p=.019$
	within	6968.3515	120.1440	58		
Interpersonal Sensitivity	between	302.4343	302.4343	1	3.241	$p=.087$ NS
	within	5800.5368	100.0093	58		
Depression	between	1350.0258	1350.0258	1	12.6842	$p=.001$
	within	6173.1774	106.4341	58		
Anxiety	between	40.4414	40.4414	1	0.3162	$p=.576$ NS
	within	7417.8697	127.8943	58		
Hostility	between	195.7696	195.7696	1	2.3231	$p=.133$ NS
	within	4887.7180	84.2710	58		
Paranoid Ideation	between	807.6223	807.6223	1	7.9090	$p=.007$
	within	5922.6182	102.1141	58		

**Table 5 - Two-way MANOVA: Total Marital Satisfaction by Status and Distress-Mothers**

MANOVA

*Covariate - time since diagnosis*

Wilks $\lambda$	Approximate $F$	df	Significance
0.98282	0.3147	3,54	$p=.815$ NS

MANOVA

*Factor - status*

Wilks $\lambda$	Approximate $F$	df	Significance
0.93433	1.26512	3,54	$p=.296$ NS

MANOVA

*Factor - distress*

Wilks $\lambda$	Approximate $F$	df	Significance
0.90830	1.81733	3,54	$p=.155$ NS

MANOVA

*Factor - status X distress*

Wilks $\lambda$	Approximate $F$	df	Significance
0.83083	3.66542	3,54	$p=.018$

Univariate ANOVA

*Dependent Variables - MAT subscales*

Subscale	Source	SS	MS	df	$F$	Signif.
Compatibility	between	410.6054	410.6054	1	3.3894	$p=.071$ NS
	within	6784.1575	121.1457	56		
Sexual Congeniality	between	34.4713	34.4713	1	7.1571	$p=.010$
	within	269.7182	4.8164	56		
Total Marital Satisfaction	between	1330.0665	1330.0665	1	5.5754	$p=.022$
	within	13359.390	238.5605	56		

**Table 6 - Two-way MANOVA: Total Marital Satisfaction by Status and Distress-Fathers**

MANOVA

Covariate - time since diagnosis

Wilks $\lambda$	Approximate $F$	df	Significance
0.97118	0.5343	3,54	$p=.661$ NS

MANOVA

Factor - status

Wilks $\lambda$	Approximate $F$	df	Significance
0.98577	0.2590	3,54	$p=.854$ NS

MANOVA

Factor - distress

Wilks $\lambda$	Approximate $F$	df	Significance
0.76833	5.4276	3,54	$p=.002$

Univariate ANOVA

Dependent Variables - MAT subscales

Subscale	Source	SS	MS	df	$F$	Signif.
Compatibility	between	539.3076	539.3076	1	9.4318	$p=.003$
	within	3202.0520	57.1795	56		
Sexual Congeniality	between	708.1333	708.1333	1	10.4093	$p=.002$
	within	3809.6116	68.0288	56		
Total Marital Satisfaction	between	2404.1470	2404.1470	1	10.5273	$p=.002$
	within	12788.886	228.3730	56		

MANOVA

Factor - status X distress

Wilks $\lambda$	Approximate $F$	df	Significance
0.91867	1.5936	3,54	$p=.202$ NS

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