

Trajectories of Adjustment in Mothers of Children with Newly Diagnosed Cancer: A Natural History Investigation

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Objectives The objectives of this study were (a) to assess negative affectivity and posttraumatic symptomatology in mothers following the diagnosis of cancer in their children; (b) to examine sociodemographic and psychosocial variables associated with change in distress over time; and (c) to identify distinct subgroups of mothers whose patterns and trajectories of adjustment can be distinguished according to available predictor data. **Methods** Two hundred and twelve mothers at seven sites were assessed just following their child's diagnosis, and again 3 months and 6 months later. Primary outcomes included measures of mood disturbance, depressive symptoms, and symptoms of posttraumatic stress.

Results Overall, mothers demonstrated a pattern of mildly elevated negative affectivity and posttraumatic symptomatology initially, with steady improvements evident at 3- and 6-month follow-up. Distinct adjustment trajectories were evident within the sample as a whole, indicating subgroups of mothers with high-declining, moderate-stable, and low-stable distress levels. **Conclusions** These findings highlight considerable resilience among mothers facing the stress of childhood cancer. Intervention efforts aimed at reducing maternal distress might best be targeted towards the subgroup of mothers who may be predicted to exhibit the highest level of distress.

Key words childhood cancer; mothers; psychosocial adjustment.

Parental adjustment to chronic and life-threatening illness in children remains an important focus of psychosocial investigation. Beyond the inherent value of identifying adjustment levels and coping patterns in this presumably distressed population, parents of seriously ill children provide a model for the study of adults under acute and prolonged exposure to stressful and potentially traumatic life events (Cooper, Baider, & Kaplan De-Nour, 1996). In addition, parental adjustment may have more far-reaching significance due to the reciprocal influences of parent, child-patient, and sibling adaptation within the dynamic family system (Dolgin & Phipps, 1996; Dolgin et al., 1997; Kazak et al., 2004a; Sahler et al., 1997; Varni, Katz, Colegrove, & Dolgin, 1996). Ultimately, the goal of

such descriptive research should be to guide intervention efforts aimed at mitigating the proximal and distal negative psychosocial effects of serious illness in the family and at promoting positive adaptation.

Empirical studies of parental adjustment to childhood cancer have documented increased levels of emotional distress, most often in the form of elevated anxiety and depression (Barrera et al., 2004; Lansky & Cairns, 1979; Landolt, Volrath, Ribl, Gnehm, & Sennhauser, 2003; Overholser & Fritz, 1990; Sloper, 2000; Steele, Dreyer, & Phipps, 2004). Noll et al. (1995) reported more psychological distress in mothers of children with cancer than in mothers of classmates without a chronic illness, but found no differences for fathers. Additional studies have

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confirmed that mothers of children with cancer experience higher levels of distress than fathers (Frank, Brown, Blount, & Bunke, 2001; Sloper, 2000). Barrera et al. (2004) found higher levels of psychological distress among mothers of children with cancer than among mothers of children with acute illnesses. Most longitudinal studies suggest that any increased levels of distress in parents of children with cancer attenuate over 6–12 months (Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Steele, Long, Reddy, Luhr, & Phipps, 2003) and may no longer be evident 1 year after diagnosis (Kupst & Schulman, 1988; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 2000). However, some longitudinal studies have found no significant decreases in symptomatology from 6- to 18-month postdiagnosis assessments (Manne, Miller, Meyers, Wollner, & Steinherz, 1996; Sloper, 2000). In terms of predictors of distress, psychosocial variables such as coping style (Barrera et al., 2004; Sloper, 2000) and social support (Frank et al., 2001; Manne, Duhamel, & Redd, 2000), have shown associations to parental adaptation levels, while more broad personality factors have received little attention.

The life-threatening nature of cancer in one's child and the ongoing exposure to the effects of the illness and treatment have led to investigations of posttraumatic stress in parents of children with cancer. These studies suggest that mothers, especially, are at risk for posttraumatic stress symptoms (PTSS), with an incidence as high as 40% (Brown, Madan-Swain, & Lambert, 2003; Hall & Baum, 1995; Kazak et al., 2004a; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Nelson et al., 1994; Pelcovitz et al., 1996; Stuber, Christakis, Houskamp, & Kazak, 1996; Stuber et al., 1994). Overall, the available data support the contention that mothers of children with cancer represent a group prone to high levels of emotional distress, and that the period following their child's diagnosis and the initiation of treatment may be particularly stressful and traumatic (Sawyer et al., 2000; Wallander & Varni, 1998).

The mother's pivotal position in the family system and the proximal and distal effects of her adaptation to the crisis of cancer in the family have led to the design of interventions aimed at reducing her distress, and at promoting her adaptive coping skills. Improving mothers' problem-solving skills, for example, has been associated with reductions in negative affectivity and PTSS (Sahler et al., 2005). Unfortunately, specific variables predictive of the natural history of maternal adaptation have not been identified. Thus, our ability to prospectively identify high-risk

subgroups of these mothers and to specifically target intervention efforts to them remains a challenge.

Studies to date of mothers' adaptation to childhood cancer have been limited by such factors as sample size and selection criteria, lack of wide geographic/cultural representation, measurement strategies that lack psychometric rigor, and use of cross-sectional rather than longitudinal designs. The current study aimed to refine our knowledge in this area by studying a large, ethnically diverse sample, and by focusing on longitudinal measurements over the critical period beginning at the initial, acute adjustment stage following diagnosis through a 6-month period of presumed medical and psychosocial stabilization.

The objectives of the current study were to: (a) document levels of negative affectivity and posttraumatic symptomatology in mothers of children with newly diagnosed cancer and how these levels change from the period immediately following diagnosis to 3- and 6-months follow-up; (b) examine demographic, cultural, personality, and psychosocial variables associated with negative affectivity and posttraumatic symptomatology over time; and (c) identify subgroups of mothers whose adjustment patterns and trajectories of adjustment are distinct and who can be distinguished according to available predictor data.

Methods

Data for the current study were obtained in the context of a larger study of the effects of a cognitive-behavioral intervention—problem solving skills training (PSST)—in reducing negative affectivity in mothers of children recently diagnosed with cancer (Sahler et al., 2005). That study was designed as a two-arm randomized clinical trial comparing PSST to usual psychosocial care (UPC), (i.e., standard psychosocial services provided by multidisciplinary teams at participating institutions). All sites involved major pediatric oncology centers with comprehensive programs of psychosocial care. With minor variations, UPC included routine social work evaluation and follow-up, psychological consultation services, and child life support. For the purposes of the current study, mothers enrolled in the UPC condition served as sample for the study of “natural history” of maternal adjustment over the initial period following their child's diagnosis. Institutional review board approval for the study was obtained at each participating site.

Participants

Participants were recruited from among mothers of children newly diagnosed with any form of cancer at

seven sites in the United States and at one site in Israel (see Sahler et al., 2005, for a description). Eligibility for participation included the following criteria: (a) having a child diagnosed with cancer; (b) ability to speak and read English or Spanish at the US sites, or English or Hebrew at the Israeli site; and (c) residence within a 50-mile radius of the study site in order to maximize participation and data completion. Participants were recruited 2–16 weeks after the child was diagnosed. This window of time was chosen as optimal, based on clinical and research experience, since it reflects the acute crisis period following evaluation and diagnosis during which the most intensive treatments are introduced. Eligible mothers were approached beginning 2 weeks post diagnosis and were enrolled as soon as they were available, emotionally and practically, for consent and participation. Monolingual Mexican-Spanish-speaking mothers were preferentially recruited to comprise ~20% of the total sample.

Detailed information regarding patterns of participation, refusal, and attrition are presented by Sahler et al. (2005). Five hundred and eighty six mothers were approached for participation in the randomized trial, of which 420 (72%) consented. The most frequent reasons

given for refusal were lack of time/too busy/schedule problems (47% of refusers), feeling overwhelmed (14%), and not interested (19%). Participants and refusers did not differ on any demographic or medical variables listed in Table I.

The sample in this report is comprised of all measurements on 212 mothers enrolled in the UPC condition, as well as preintervention assessments on 217 mothers enrolled in the UPC + PSST condition. While mothers from this later group are not available for follow-up, including them increases our precision of the baseline estimates and the power to identify association of demographic characteristics with early distress. Demographic and medical characteristics of the participating mothers and their children with cancer are presented in Table I. Ninety percent of the sample completed all assessments. Loss to follow-up was associated only with maternal education, with higher rates of missing data associated with lower educational level (Kendall's τ - $b = -.11$, $p = .006$ at time 2; Kendall's τ - $b = -.08$, $p = .047$ at time 3). Loss to follow-up was not significantly associated with baseline scores on any of the measures. Five mothers withdrew from the study for reasons related to their own

Table I. Demographic Characteristics of Participating Mothers and their Children with Cancer

Mothers' Characteristics	T1–T3	T1 only	Children's characteristics	T1–T3	T1 only
Mean age (years)	36	35	Mean age at diagnosis	7.6	7.6
Education (%)			Gender (%)		
<High school	11	11	Male	55	47
High school	40	36	Female	45	53
Postsecondary	39	36	Diagnosis (%)		
Graduate school	8	13	Leukemia	43	42
Marital status (%)			Brain tumor	18	12
Single	6	11	Other tumor	27	32
Married	69	69	NonHodgkin's lymphoma	9	7
Divorced (single)	9	9	Hodgkin's disease	3	6
Divorced (remarried)	5	3			
Unmarried with partner	9	7			
Ethnicity—race (%)					
White, not Hispanic	52	48			
Hispanic	28	24			
Black, not Hispanic	3	8			
American Indian	1	2			
Asian	1	2			
Other (mixed)	13	13			
Primary language (%)					
English	66	66			
Spanish	21	21			
Hebrew	13	13			

Mothers on control arm ($n = 212$) contributed data at T1, T2, and T3; mothers on intervention arm ($n = 217$) contributed data only at T1.

or their child's poor health status. Assessments obtained prior to withdrawal are included in the analysis.

Procedures

Each mother meeting eligibility criteria was approached in accordance with local institutional review board criteria. Study measures were administered at three time points: (a) T1, 2–16 weeks following diagnosis; (b) T2, 12 weeks after T1; and (c) T3, 24 weeks after T1. On average for the sample as a whole, these assessments took place at 8.8 ($SD = 4.5$), 20.8 ($SD = 5.9$), and 30.0 ($SD = 6.4$) weeks postdiagnosis. Demographic and medical data were recorded at T1. The measures employed in this study were administered in a standardized fashion across all study sites. Language adaptation, where necessary, was achieved through translation and back-translation by native-speaking experts in psychology and translation. Regional variations in the way language is used were incorporated in to the translations. Native-speaking research assistants remained available for clarification during administration of the measures. Basic orientation and training of all research assistants included a “Cross-cultural Considerations” module. Each participant received a stipend of \$100 when the final assessment was completed.

Outcome Measures

Profile of Mood States (POMS)

The POMS is a 65-item inventory of positive and negative adjectives used to describe feelings during the last week. Subjects respond to each item by endorsing it on a 5-point scale ranging from 1 (not at all) to 5 (extremely). The scale produces six subscales (Tension/Anxiety, Depression/Dejection, Anger/Hostility, Fatigue, Confusion, and Vigor). The individual subscales scores are combined to produce a POMS Total Mood Disturbance (TMD) score, which is the sum of the five negative affect scales minus the vigor scale. Thus, higher scores reflect greater mood disturbance (negative affectivity). The POMS is a widely used measure whose psychometric properties are well documented. (McNair, Lorr, & Droppleman, 1992). Internal reliabilities for the six subscales range from .84 to .95, and 6-week stability coefficients range from .65 to .74.

Beck Depression Inventory-II (BDI-II)

This 21-item self-report measure assesses the cognitive, affective, and behavioral components of depressive symptoms (Beck, Steer, Ball, Ciervo, & Kabat, 1997). It is widely used for both clinical and research purposes.

Internal consistency and test–retest reliabilities are both reported as $>.90$.

Impact of Event Scale-Revised (IES-R)

The IES-R (Weiss & Marmar, 1997) assesses the construct of perceived posttraumatic stress as a component of negative affectivity. This 22-item self-report measure includes three subscales (Intrusion, Avoidance, and Hyperarousal) that assess PTSS experienced during the preceding week in response to a specific event. Mothers were asked to complete the IES-R “with respect to your child's cancer”, referencing the cancer experience specifically. The IES-R Total Score is the sum of the three subscales and is the outcome reported in the analyses that follow. The IES-R has been used widely to measure PTSS associated with significant events, such as diagnosis of cancer. Internal consistency reliabilities of the Intrusion, Avoidance, and Hyperarousal subscales are .91, .84, and .90, respectively.

Predictive Measures

NEO-Five Factor Inventory (NEO-FFI)

The NEO-FFI is a 60-item scale that measures five major dimensions of personality, as derived from decades of factor analytic research on the structure of personality that have resulted in the five-factor model (Costa & McCrae, 1992; Digman, 1990). As such, the NEO is a measure of *normal* personality traits with demonstrated utility in clinical and research settings. The five domains measured include Neuroticism (N), Extraversion (E), Openness (O), Agreeableness (A), and Conscientiousness (C). The NEO-FFI is a shortened form of the revised NEO Personality Inventory (NEO PI-R). The reliability and validity of the NEO are well established, and it is one of the most widely used measures of personality in adults. Psychometric properties of the shorter NEO-FFI range between .68 and .86, and correlations with the longer factors range from .75 to .89 (Costa & McCrae, 1992).

Social Problem-Solving Inventory-Revised (SPSI-R)

The SPSI-R is a 52-item instrument measuring five dimensions of problem solving (D'Zurilla & Nezu, 1990). Respondents endorse statements by rating them on a 5-point scale ranging from 1 (not at all true) to 5 (extremely true). The SPSI-R distinguishes between problem orientation, which, as an appraisal, can be positive or negative, and problem solving, which, as a strategic approach, can be rational or characterized by impulsivity–carelessness or avoidance. The sum of positive problem orientation and rational problem solving

is termed constructive problem solving; the sum of negative problem orientation, impulsivity-carelessness style, and avoidance style is termed dysfunctional problem solving. The SPSI-R Total Score (0–20) is the weighted average of the five subscores and constitutes the major outcome variable reported here. A higher total score indicates better problem-solving skills. The SPSI-R has been shown to maintain its factor structure following translation and adaptation to various language and cultural groups (e.g., Maydeu-Olivares, Rodriguez-Fornells, Gomez-Benito, & D’Zurilla, 2000; Siu & Shek, 2005).

Data Analysis

A mixed-effects piece-wise linear growth-curve model was used to model changes in the outcome over time which was measured as the time between the child’s diagnosis and the mother’s assessment. The slope was allowed to change at T2 and T3. Two random effects were included allowing variation among subjects in their initial scores (intercept) and rate of change over time (slope). The test of the effects of potential predictors was based on time-invariant effects and time-dependent changes between T1, T2, and T3. If this overall test was not significant, the predictor was dropped from the model. Potential predictors included the child’s age and gender, diagnoses of leukemia and of a brain tumor, mother’s age, ethnicity and language, years of education, marital status, NEO-FFI, and SPSI-R scores. Because the distribution of BDI-II scores is right skewed, we used a square root transformation of the BDI-II scores in the analysis to provide a symmetric distribution of scores.

A semiparametric group-based method described by Nagin (Nagin, 1999; Nagin & Tremblay, 2001) was used to identify distinctive groups of individual trajectories within a sample. Programs written to run in SAS were used for these analyses (Jones, Nagin, & Roeder, 2001).

Models were developed assuming one, two, three and four groups and compared using the Bayesian information criterion (BIC). Initial models included linear and quadratic terms in the fixed effects and a constant between subject random effect; nonsignificant terms were eliminated. Kendall’s tau-*b* was used to estimate the correlations between potential predictors and the probability of belonging to the group of individuals with a common trajectory. Within each group, multiple comparison adjustments were performed using Hochberg’s modification of the Bonferroni procedure (Hochberg, 1988).

Results

Maternal Adjustment

Table II presents the outcome measures of negative affectivity and PTSS at each of the three assessment points. These results demonstrate significant decreases in negative affectivity, as measured by the POMS-TMD and the BDI-II, from T1 to T2 and from T2 to T3. Similarly, all three subscales of the IES-R showed declines in PTSS from T1 to T3, with the most pronounced declines appearing in the Intrusion and Hyperarousal subscales between T1 and T2.

Predictors of Maternal Adjustment

In examining the demographic, cultural, personality, and psychosocial variables associated with negative affectivity and posttraumatic symptomatology over time, the initial predictive model included all of the demographic characteristics and cultural groups interacting with time. Within this expanded model, child’s age, gender, diagnosis of a brain tumor or leukemia, mother’s age, marital status, education, and the miscellaneous cultural group (African American, American Indian, and Asian) were not significantly related to any of the

Table II. Negative Affectivity and Posttraumatic Stress at T1, T2, and T3^a

Outcome Measure	T1	T2	T3	T1 vs. T2		T1 vs. T3		T2 vs. T3	
	Mean (SD)	Mean (SD)	Mean (SD)	<i>t</i> -value	<i>p</i>	<i>t</i> -value	<i>p</i>	<i>t</i> -value	<i>p</i>
POMS-TMD	47.0 (38.9)	39.6 (37.4)	33.9 (37.3)	−3.09	.002	−5.1	<.001	−2.42	.016
BDI (sqrt)	3.64 (1.30)	3.46 (1.43)	3.25 (1.45)	−2.17	.03	−4.62	<.001	−2.41	.016
BDI (untransformed)	13.2	12.0	10.6						
IES-R									
Total score	32.0 (17.6)	27.9 (18.2)	27.2 (17.6)	−3.93	<.001	−4.75	<.001	−.71	n.s.
Intrusion	12.8 (6.7)	10.7 (6.8)	10.9 (6.5)	−5.33	<.001	−4.90	<.001	.75	n.s.
Avoidance	9.5 (6.6)	8.8 (6.9)	8.3 (6.5)	−1.66	n.s.	−2.81	.005	−1.37	n.s.
Hyperarousal	9.6 (6.7)	8.4 (6.7)	8.0 (6.6)	−3.14	.002	−4.7	<.001	−1.26	n.s.

^aT1, 2–16 weeks following diagnosis; T2, 3 months after T1; T3, 6 months after T1.

Table III. Predictors of Adjustment Trajectory

	POMS-TMD	BDI	IES-R
Low-stable distress	Less neurotic ($r = .46^{***}$)	Less neurotic ($r = .26^{***}$)	Less neurotic ($r = .32^{***}$)
	Better problem solving ($r = .27^{***}$)	Better problem solving ($r = .16^{***}$)	Better problem solving ($r = .25^{***}$)
	Non-Israeli ($r = .22^{***}$)	Non-Israeli ($r = .13^{**}$)	Non-Israeli ($r = .26^{***}$)
	More agreeable ($r = .21^{***}$)	More agreeable ($r = .12^{**}$)	More agreeable ($r = .18^{***}$)
	More extraverted ($r = .19^{***}$)	More extraverted ($r = .13^{**}$)	More extraverted ($r = .10^*$)
	Higher education level ($r = .10^*$)	higher education level ($r = .13^*$)	Higher education level ($r = .18^{***}$)
	Younger child ($r = .11^*$)		NonHispanic/Spanish speaking ($r = .31^{***}$)
Moderate-stable distress	More neurotic ($r = .32^{***}$)	More neurotic ($r = .26^{***}$)	More neurotic ($r = .24^{***}$)
	Israeli ($r = .21^{***}$)	Israeli ($r = .14^{**}$)	Israeli ($r = .28^{***}$)
	Less agreeable ($r = .10^*$)	Less agreeable ($r = .12^*$)	Less agreeable ($r = .15^{**}$)
	Poorer problem solving ($r = .18^{***}$)	Poorer problem solving ($r = .16^{***}$)	Poorer problem solving ($r = .15^{***}$)
	Less extraverted ($r = .16^{**}$)	Less extraverted ($r = .13^{**}$)	
High-declining distress	Single mothers ($r = .19^{***}$)		Lower education level ($r = .12^{**}$)
	More neurotic ($r = .21^{***}$)	n/a	Hispanic/Spanish speaking ($r = .21^{***}$)
	Poorer problem solving ($r = .13^{**}$)		More neurotic ($r = .33^{***}$)
	Less agreeable ($r = .10^*$)		Poorer problem solving ($r = .22^{***}$)
	Single mothers ($r = .11^*$)		Less agreeable ($r = .14^{**}$)
			Israeli ($r = .20^{***}$)
			Hispanic/Spanish speaking ($r = .21^{***}$)
		Lower education level ($r = .11^*$)	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

outcome measures. These covariates were dropped from further analysis. Significant demographic predictor variables are detailed subsequently and summarized in Table III. Variables were coded such that the reference (or “average”) mother was 35 years of age with some college education, married, English-speaking, nonHispanic, nonIsraeli, Caucasian, with an 8-year-old female child. The reference mother had a NEO score of 50 and a SPSI total score of 14.

POMS-TMD scores over time were significantly predicted by NEO-N (neuroticism) and SPSI-R scores. In comparison to the reference mother, POMS-TMD scores at T1 were elevated by 0.72 *SD* in mothers with NEO-N scores 1 *SD* above the NEO-N reference mean (i.e., mean score of reference mother, $p < .001$), and by 0.17 *SD* in mothers with SPSI-R scores 1 *SD* below the SPSI-R reference mean ($p = 0.014$). There was a decline of 0.49 *SD* from T1 to T2 in the reference mother POMS-TMD scores ($p < 0.001$) and an additional marginal decline of 0.25 *SD* for mothers with elevated NEO-N scores (1 *SD* above the NEO-N mean), over the same period ($p = 0.060$). Scores remained stable from T2 to T3.

BDI-II scores for the reference group decreased 0.19 *SD* ($p = .12$) between T1 and T2, and 0.12 *SD* ($p = .33$) from T2 to T3 with the total change from T1 to T3 being statistically significant ($p = .006$). BDI-II scores were significantly higher in mothers with elevated NEO-N

scores and lower SPSI-R scores. In comparison to the reference mother, BDI-II scores at T1 were elevated by 0.51 *SD* in mothers with NEO-N scores 1 *SD* above the NEO-N reference mean ($p < .001$), and 0.15 *SD* in mothers with SPSI-R scores 1 *SD* below the SPSI-R reference mean ($p = 0.028$). There were no differences in the rate of change in BDI-II scores associated with NEO-N scores.

In contrast to the similar predictor patterns for the POMS-TMD and the BDI-II, the predictor pattern for the IES-R was different. IES-R scores at T1 were significantly higher (1.08 *SD*) for Hispanic mothers whose primary language was Spanish ($p < .001$), and 0.55 *SD* higher in mothers with elevated NEO-N scores 1 *SD* above the NEO-N reference mean ($p < .001$). IES-R scores at T1 were also marginally elevated (0.31 *SD*) in Israeli mothers ($p = .065$) and 0.11 *SD* higher in mothers with lower SPSI-R scores ($p = .091$). IES-R scores decreased 0.56 *SD* from T1 to T2 in all mothers ($p < .001$), except Israeli mothers who experienced an increase (.39 *SD*) during the same period ($p < .001$). Scores were stable between T2 and T3.

Trajectories of Maternal Adjustment

In an effort to identify subgroups of mothers whose patterns and trajectories of adjustment are distinct from one another, and who can be distinguished according to

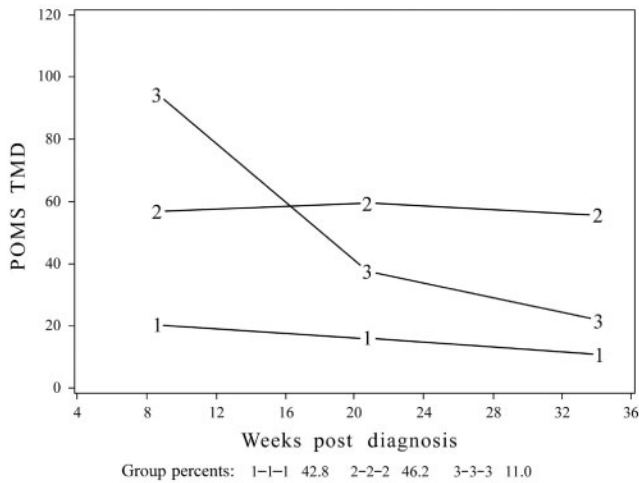


Figure 1. Trajectory patterns for POMS-TMD.

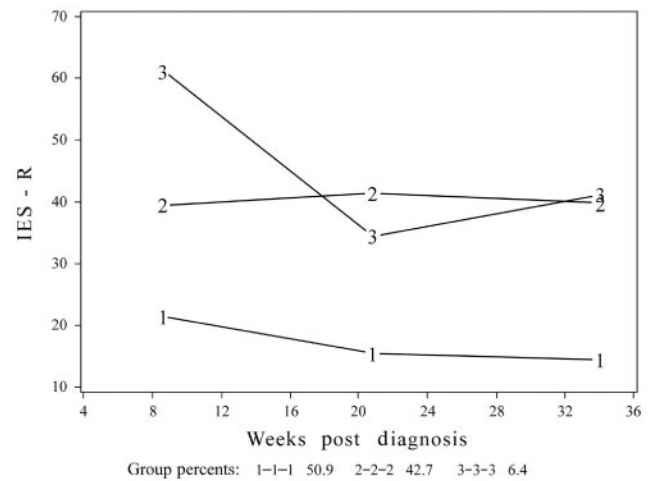


Figure 3. Trajectory patterns for IES-R.

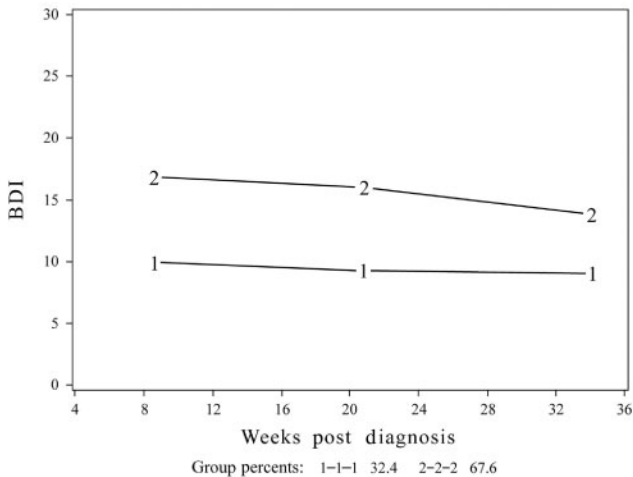


Figure 2. Trajectory patterns for BDI-II.

available predictor data, we used a semiparametric group-based analysis (Nagin, 1999; Nagin & Tremblay, 2001). In order to ascertain whether these trajectory patterns varied by study site, we included a random site effect into the models. However, for each of the outcomes this component of variation was not significantly different from zero (POMS-TMD: $z = 0.52$, $p = .30$; BDI-II: $z = 0.61$, $p = .27$; IES-R: $z = 0.83$, $p = .20$).

For the POMS-TMD, our modeling yielded three distinct subgroups of mothers: mothers whose mood disturbance scores were low and stable across the three assessment points (43%), mothers whose mood disturbance scores were at a moderate level and stable over time (46%), and a small but distinct subgroup of mothers (11%) whose mood disturbance was initially very high,

declining steadily over time (Fig. 1). For the BDI-II, our modeling yielded two distinct subgroups of mothers. Approximately one third of the sample consisted of mothers whose depression scores were low and stable across the three assessment points (32%). For about two-thirds of the sample (68%), depression scores were significantly higher initially, declining only slightly over time (Fig. 2). Our modeling for the IES-R yielded three distinct subgroups of mothers. Approximately half of the sample (51%) consisted of mothers whose levels of PTSS were low and stable across time. Another large portion of the sample (43%) was comprised of mothers whose IES-R scores were moderate over time. Finally, a small but distinct subgroup of mothers (6%) exhibited very high levels of posttraumatic symptomatology initially that declined to moderate levels by 3 months postdiagnosis (Fig. 3).

Based on these trajectory patterns, we were able to identify three subgroups of mothers whose adjustment levels over time are distinct: those with Low-stable distress, those with Moderate-stable distress, and those with High-declining distress. In an effort to characterize these subgroups according to available demographic and psychological predictor data, we estimated the correlations between these predictors and the likelihood of membership in each of these trajectory groups. Table III summarizes those predictor variables that were found to be significantly correlated with group membership for each of the three outcome measures.

A relatively consistent pattern is evident whereby mothers with Low-stable distress tend to be less neurotic, better problem solvers, more agreeable and extraverted, better educated, nonIsraeli, and in the case of the IES-R,

nonHispanic/Spanish speaking. Mothers with Moderate-stable distress levels tend to be more neurotic, poorer problem solvers, and less agreeable and extraverted. Single, Israeli, and Hispanic/Spanish speaking mothers also tend to fall into this category. The demographic and psychological predictors of membership in the High-declining distress group are generally similar to those of the Moderate-stable distress group. In this respect, it should be noted that the high-declining distress group that emerged on the POMS-TMD and IES-R included only relatively small proportions of the total sample (11% and 6%, respectively).

Discussion

Within the growing body of literature on parental adaptation to chronic childhood illness, the current study offers confirmation of some earlier assumptions, clarification of others, and implications for further research. Its power to do so derives from its prospective longitudinal design over a well-defined period of time, its relatively large sample size, sound measurement strategies, and its broad geographic and cultural representation.

Taken as a single group, mothers of children with cancer in our sample were found to display moderate elevations in negative affectivity and PTSS during the period following diagnosis (on average 2 months). Distress declined steadily at 3- and 6-month follow-up. Mood disturbance and depression, as measured by the POMS-TMD and the BDI-II, respectively, improved from T1 to T2 and from T2 to T3. PTSS, as measured by the IERS-R, also diminished significantly over this time period, most notably in Intrusion and Hyperarousal symptomatology. These findings are in line with previous studies documenting moderate initial levels of distress that diminish over the year following diagnosis (Dahlquist, Czyzewski, & Jones, 1996; Kupst & Schulman, 1988; Manne et al., 1996; Sawyer et al., 2000; Steele et al., 2003). Our findings go further to suggest that a significant reduction in negative affectivity and PTSS is evident as early as 5 months postdiagnosis, the average time of our T2 assessment.

In the absence of a control group of mothers of healthy children, and in an effort to appreciate the levels of observed distress in our sample in comparative terms, we searched the literature for studies utilizing similar measures with nonclinical and reference samples. Garrity and Demick (2001) found no gender differences in their sample of healthy adults, with a POMS-TMD score calculated at 30.1, markedly lower than the scores

found in our sample at T1 (47.0) and T2 (39.6), but approaching T3 (33.9) levels of mood disturbance. Oliver and Simmons (1985) reported BDI scores calculated to have a square root score of 2.62 for a random sample of adult women, again lower than scores obtained in our sample at T1 (3.64), T2 (3.46), and T3 (3.25). At all three assessment points, mothers of children with cancer in our sample scored higher on the IES-R Intrusion ($p < .01$) and Avoidance ($p < .01$) subscales than control mothers of healthy children reported by Barakat et al. (1997). In the current sample, IES-R scores at baseline (T1) were slightly higher than those reported for mothers of long-term survivors of childhood cancer (Kazak et al., 2004a,b), but by T2 they had declined to comparable levels. Thus, although our design did not include a control group of mothers of healthy children, comparison to previously published data suggest that the observed distress levels in the current sample are moderately elevated just following diagnosis and decline over time.

The adaptation pattern evident here must be reconciled with those studies suggesting prolonged parental distress. Sloper (2000) reported high levels of distress for mothers and fathers at 6- and 18-months postdiagnosis, with little change over time. However, that study focused specifically on psychosomatic complaints and did not include data on earlier levels of postdiagnosis distress, which were the focus of our assessment. Thus, meaningful comparisons are difficult. While increased levels of posttraumatic symptomatology have been reported in parents of childhood cancer survivors (e.g., Brown et al., 2003; Kazak et al., 2004a), fewer studies have addressed PTSS among parents during the active treatment phase. Landolt et al. (2003) reported higher levels of PTSS in mothers of children with newly diagnosed cancer as compared to other pediatric populations; however, no longitudinal follow-up data were presented. Kazak et al. (2005) reported higher levels of PTSS among parents of children during active treatment than among a referent group of parents of childhood cancer survivors. However, in contrast to the current findings, they found no relationship between PTSS as measured by the IES-R and time since diagnosis. This lack of association with time might reflect the fact that (Kazak et al., 2005) sample was assessed at a mean 15 months after diagnosis, and presumably the majority of the sample were beyond the 2–5 month window where the majority of decline was observed in the current study. In contrast, and more consistent with the present findings, Phipps, Long, Hudson, and Rai (2005), reported significant differences on the IES-R between parents of

recently diagnosed patients and parents of long-term survivors.

Factors predicting parental adjustment to childhood cancer have been the subject of prior research, often focusing on such variables as social support and parental coping style (e.g., Frank et al., 2001; Hoekstra-Weebers et al., 2001; Manne et al., 2000). Here it emerged that maternal personality traits (i.e., neuroticism) and problem solving ability significantly predicted initial distress levels, as well as the rate of improvement over time. Mothers with higher levels of neuroticism and poorer problem solving skills had increased negative affectivity and PTSS at T1. Maternal neuroticism was a significant predictor of POMS-TMD change scores from T1 to T2.

Culture and language also emerged as significant predictors, specifically in relation to posttraumatic symptomatology. Hispanic mothers whose primary language was Spanish, as well as Israeli mothers, reported higher levels of PTSS than reference mothers at T1. In addition, Israeli mothers' PTSS levels did not diminish over time in the same fashion as the sample as a whole. One possible explanation for this is that other cumulative stressors not specifically measured here (e.g., immigration, acculturation, terror) might act to increase susceptibility to PTSS. Perhaps this serves as a reminder that having a child with cancer is not the only stressor, or in some cases, even the primary stressor that parents may be experiencing. Assessing concurrent stressors and their contribution to PTSS is recommended in future research. These findings underline the contribution of personality and sociocultural characteristics to parental adjustment and the importance of pursuing this area of investigation.

We were able to identify specific trajectories of maternal adjustment over time, with three distinct patterns emerging from the sample as a whole: mothers whose initial distress levels were comparatively low and remained so over time (Low-stable); mothers who exhibited moderate levels of initial distress that remained so over time (Moderate-stable); and mothers who had high initial distress levels that declined over time (High-declining). This being so, it may be misleading to interpret longitudinal findings from whole, undifferentiated samples that are, in fact, comprised of distinct subsamples. This has implications on a number of levels. First, it may explain the variable findings among studies of maternal adjustment and its dynamics over time, as described earlier. Second, it may be less informative to seek out predictors of adjustment for whole samples than to identify the distinguishing characteristics of distinct subsamples. Third, and perhaps most important,

trajectory analyses such as employed here may help identify to whom intervention efforts need be targeted, and where these efforts may be spared.

Our model suggests that quantifiable personality characteristics (neuroticism, extraversion, agreeability, problem-solving ability) in combination with readily available sociodemographic data (marital status, ethnicity, education level) can meaningfully predict adjustment trajectory. This lends itself to the development of screening tools to assist in targeting intervention and allocating clinical resources. Perhaps even more directly, a simple measure of distress at baseline can serve to target those in need of intervention. Between one-third and one-half of our total sample had a Low-stable distress trajectory, suggesting that delayed distress, or late-onset adjustment difficulties are unlikely to be seen in parents who are doing well initially, given that their children continue to do well. It should be noted that the children of the mothers in this study were all clinically stable during this early stage of treatment. Targeting Moderate-stable and High-declining distress trajectory individuals for intervention would be clinically most sensible as well as resource efficient. Further research is needed to replicate these findings and to incorporate other relevant predictor variables (e.g., social support, coping style) in order to arrive at still more refined formulas for predicting adjustment trajectory, and psychological distress over time.

The methodological strengths of the current study notwithstanding, several limitations must be noted. The initial assessment window of 2–16 weeks was chosen for reasons described earlier, yet still represents a broad enough time frame to allow for considerable variability in adjustment levels between mothers. Also, the inclusion of a true control group consisting of mothers of healthy children would have elucidated the adjustment levels of the mothers studied here, without reliance on normative and reference samples reported elsewhere. Finally, while our predictor and outcome measures do reflect trait and state characteristics, respectively, the possibility of shared measurement variance must be considered.

Theoretically, these findings of moderate distress that declines significantly over time are not supportive of general stress and trauma models (Thompson, Gil, Burbach, & Keith 1993; Wallander, Varni, Babani, Bani, & Wilcox, 1989) that hypothesize direct links between the presence of a chronic illness and dysfunctional outcomes. The results from this investigation are, however, congruent with the conclusions of Bonanno (2004), who suggests that resilience among adults

represents the most prevalent and common response to adverse events. From the perspective of evolutionary biology, these findings suggest that randomly occurring stressful or traumatic life events do not alter our potential for inclusive fitness by negatively affecting emotional well-being over time (Archer, 1996).

Empirically validated intervention approaches to improving parental adaptation to childhood cancer are increasingly available. Kazak et al. (2004b) report on a promising four-session intervention integrating cognitive-behavioral and family therapy approaches to reduce posttraumatic symptomatology in childhood cancer survivors and their parents. Our own group has demonstrated the utility of an eight-session cognitive-behavioral intervention based on problem-solving skills training to reduce negative affectivity and PTSS in mothers of newly diagnosed children with cancer (Sahler et al., 2005). Improved targeting of those in greatest need, based on anticipated adjustment trajectories, will likely lead to even more robust intervention effects than have been evident to date.

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References

- Archer, J. (1996). Sex differences in social behavior: Are the social role and evolutionary explanations compatible? *American Psychologist*, *51*, 909–917.
- Barakat, L. P., Kazak, A. E., Meadows, A. T., Casey, R., Meeske, K., & Stuber, M. L. (1997). Families surviving childhood cancer: A comparison of post-traumatic stress symptoms with families of healthy children. *Journal of Pediatric Psychology*, *22*, 843–859.
- Barrera, M., D'Agostino, N. M., Gibson, J., Gilbert, T., Weksberg, R., & Malkin, D. (2004). Predictors and mediators of psychological adjustment in mothers of children newly diagnosed with cancer. *Psycho-Oncology*, *13*, 630–641.
- Beck, A. T., Steer, R. A., Ball, R., Ciervo, C. A., & Kabat, M. (1997). Use of the Beck anxiety and depression inventories for primary care with medical outpatients. *Assessment*, *4*, 211–219.
- Bonanno, G. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist*, *59*, 20–28.
- Brown, R. T., Madan-Swain, A., & Lambert, R. (2003). Posttraumatic stress symptoms in adolescent survivors of childhood cancer and their mothers. *Journal of Traumatic Stress*, *16*, 309–318.
- Cooper, C., Baider, L., & Kaplan De-Nour, A. (Eds), (1996). *Cancer and the family*. London: John Wiley and Sons.
- Costa, P. T., & McCrae, R. R. (1992). *Revised NEO Personality Inventory (NEO-PI-R) and the NEO Five-Factor Inventory (NEO-FFI): Professional Manual*. Lutz, FL: Psychological Assessment Resources, Inc.
- Dahlquist, L. M., Czyzewski, D. I., & Jones, C. L. (1996). Parents of children with cancer: A longitudinal study of parental distress, coping style, and marital adjustment two and twenty months after diagnosis. *Journal of Pediatric Psychology*, *21*, 541–554.
- Digman, J. M. (1990). Personality structure: Emergence of the five-factor model. *Annual Review of Psychology*, *41*, 417–440.
- Dolgin, M. J., Blumensohn, R., Mulhern, R. K., Orbach, J., Sahler, O. J., Roghmann, K. J., et al. (1997). Sibling adaptation to childhood cancer collaborative study: Cross-cultural aspects. *Journal of Psychosocial Oncology*, *15*, 1–14.
- Dolgin, M. J., & Phipps, S. (1996). Reciprocal influences in family adjustment to childhood cancer. In L. Baider, C. Cooper, & A. Kaplan de-Nour (Eds.), *Cancer and the family* (pp. 73–92). Oxford England: John Wiley & Sons.
- D'Zurilla, T. J., & Nezu, A. M. (1990). Development and preliminary evaluation of the Social Problem-Solving Inventory. *Psychological Assessment*, *2*, 156–163.
- Frank, N. C., Brown, R. T., Blount, R. L., & Bunke, V. (2001). Predictors of affective responses of mothers and fathers of children with cancer. *Psychooncology*, *10*, 293–304.
- Garrity, R. D., & Demick, J. (2001). Relations among personality traits, mood states, and driving behaviors. *Journal of Adult Development*, *8*, 109–118.
- Hall, M., & Baum, A. (1995). Intrusive thoughts as determinants of distress in parents of children with cancer. *Journal of Applied Social Psychology*, *25*, 1215–1230.
- Hochberg, Y. (1988). A sharper Bonferroni procedure for multiple significance testing. *Biometrika*, *75*, 800–803.

- Hoekstra-Weebers, J. E. H. M., Jaspers, J. P. C., Kamps, W. A., & Klip, E. C. (2001). Psychologic adaptation and social support of parents of pediatric cancer patients: A prospective longitudinal study. *Journal of Pediatric Psychology*, *26*, 225–235.
- Jones, B. L., Nagin, D. S., & Roeder, K. (2001). A SAS procedure based on mixture models for estimating developmental trajectories. *Sociological Methods & Research*, *29*, 374–393.
- Kazak, A. E., Alderfer, M., Rourke, M. T., Simms, S., Streisand, R., & Grossman, J. R. (2004a). Posttraumatic stress disorder (PTSD) and posttraumatic stress symptoms (PTSS) in families of adolescent childhood cancer survivors. *Journal of Pediatric Psychology*, *29*, 211–219.
- Kazak, A. E., Alderfer, M. A., Streisand, R., Simms, S., Rourke, M. T., Barakat, L. P., et al. (2004b). Treatment of posttraumatic stress symptoms in adolescent survivors of childhood cancer and their families: A randomized clinical trial. *Journal of Family Psychology*, *18*, 493–504.
- Kazak, A. E., Boeving, C. A., Alderfer, M. A., Hwang, W., & Reilly, A. (2005). Posttraumatic stress symptoms during treatment in parents of children with cancer. *Journal of Clinical Oncology*, *23*, 7405–7410.
- Kupst, M. J., & Schulman, J. L. (1988). Long-term coping with pediatric leukemia: A six-year follow-up study. *Journal of Pediatric Psychology*, *13*, 7–22.
- Landolt, M. A., Volrath, M., Ribi, K., Gnehm, H. E., & Sennhauser, F. H. (2003). Incidence and associations of parental and child posttraumatic stress symptoms in pediatric patients. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, *44*, 1199–1207.
- Lansky, S. B., & Cairns, N. U. (1979). *The family of the child with cancer*. New York: American Cancer Society.
- Manne, S., DuHamel, K., & Redd, W. H. (2000). Association of psychological vulnerability factors to post-traumatic stress symptomatology in mothers of pediatric cancer survivors. *Psycho-Oncology*, *9*, 372–384.
- Manne, S., Miller, D., Meyers, P., Wollner, N., & Steinherz, P. (1996). Depressive symptoms among parents of newly diagnosed children with cancer: A 6-month follow-up study. *Children's Health Care*, *25*, 191–209.
- Maydeu-Olivares, A., Rodriguez-Fornells, A., Gomez-Benito, J., & D'Zurilla, T. J. (2000). Psychometric properties of the Spanish adaptation of the SPSI-R. *Personality and Individual Differences*, *29*, 699–708.
- McNair, D. M., Lorr, M., & Droppleman, L. F. (1992). *Manual for the Profile of Mood States*. San Diego, CA: Educational and Industrial Testing Service.
- Nagin, D. (1999). Analyzing developmental trajectories: A semiparametric, group-based approach. *Psychological Methods*, *4*, 139–177.
- Nagin, D., & Tremblay, R. E. (2001). Analyzing developmental trajectories of distinct but related behaviors: A group-based method. *Psychological Methods*, *4*, 139–177.
- Nelson, A. E., Miles, M. S., Reed, S. B., Davis, C. P., & Cooper, H. (1994). Depressive symptomatology in parents of children with chronic oncologic or hematologic disease. *Journal of Psychosocial Oncology*, *12*, 61–75.
- Noll, R. B., Gartstein, M. A., Hawkins, A., Vannatta, K., Davies, W. H., & Bukowski, W. M. (1995). Comparing parental distress for families with children who have cancer and matched comparison families without children with cancer. *Family Systems Medicine*, *13*, 11–28.
- Oliver, J. M., & Simmons, M. E. (1985). Affective disorders and depression as measured by the Diagnostic Interview Schedule and the Beck Depression Inventory in an unselected adult population. *Journal of Clinical Psychology*, *41*, 469–477.
- Overholser, J. C., & Fritz, G. K. (1990). The impact of childhood cancer on the family. *Journal of Psychosocial Oncology*, *8*, 71–85.
- Pelcovitz, D., Goldenberg, B., Kaplan, S., Weinblatt, M., Mandel, F., Meyers, B., et al. (1996). Posttraumatic stress disorder in mothers of pediatric cancer survivors. *Psychosomatics*, *37*, 116–126.
- Phipps, S., Long, A., Hudson, M., & Rai, S. N. (2005). Symptoms of post-traumatic stress in children with cancer and their parents: Effects of informant and time from diagnosis. *Pediatric Blood & Cancer*, *45*, 952–959.
- Sahler, O. J., Fairclough, D. L., Phipps, S., Mulhern, R. K., Dolgin, M. J., & Noll, R. B. (2005). Using problem-solving skills training to reduce negative affectivity in mothers of children with newly diagnosed cancer: Report of a multisite randomized trial. *Journal of Consulting & Clinical Psychology*, *73*, 272–283.
- Sahler, O. J., Roghmann, K. J., Mulhern, R. K., Carpenter, P. J., Sargent, J. R., & Copeland, D. R.

- (1997). Sibling Adaptation to Childhood Cancer Collaborative Study: The association of sibling adaptation with maternal well-being, physical health, and resource use. *Journal of Developmental & Behavioral Pediatrics, 18*, 233–243.
- Sawyer, M., Antoniou, G., Toogood, I., Rice, M., & Baghurst, P. (2000). Childhood cancer: A 4-year prospective study of the psychological adjustment of children and parents. *Journal of Pediatric Hematology/Oncology, 22*, 214–220.
- Siu, A. M., & Shek, D. T. (2005). The Chinese version of the SPSI: Some initial results on reliability and validity. *Journal of Clinical Psychology, 61*, 347–360.
- Sloper, P. (2000). Predictors of distress in parents of children with cancer: A prospective study. *Journal of Pediatric Psychology, 25*, 91.
- Steele, R. G., Dreyer, M. L., & Phipps, S. (2004). Patterns of maternal distress among children with cancer and their association with child emotional and somatic distress. *Journal of Pediatric Psychology, 29*, 507–517.
- Steele, R. G., Long, A., Reddy, K. A., Luhr, M., & Phipps, S. (2003). Changes in maternal distress and child-rearing strategies across treatment for pediatric cancer. *Journal of Pediatric Psychology, 28*, 447–452.
- Stuber, M. L., Christakis, D. A., Houskamp, B., & Kazak, A. E. (1996). Posttrauma symptoms in childhood leukemia survivors and their parents. *Psychosomatics, 37*, 254–261.
- Stuber, M. L., Gonzales, S., Meeske, K., Guthrie, D., Houskamp, B. M., & Pynoos, R. (1994). Post-traumatic stress after childhood cancer II: A family model. *Psycho-Oncology, 3*, 313–319.
- Thompson, R., Gil, K., Burbach, D., & Keith, B. R. (1993). Psychological adjustment of mothers of children and adolescents with sickle cell disease: The role of stress, coping methods, and family functioning. *Journal of Pediatric Psychology, 18*, 549–559.
- Varni, J. W., Katz, E. R., Colegrove, R. J., & Dolgin, M. (1996). Family functioning predictors of adjustment in children with newly diagnosed cancer: A prospective analysis. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 37*, 321–328.
- Wallander, J. L., & Varni, J. W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 39*, 29–46.
- Wallander, J. L., Varni, J. W., Babani, L., Banis, H. T., & Wilcox, N. J. (1989). Disability parameters, chronic strain, and adaptation of physically handicapped children and their mothers. *Journal of Pediatric Psychology, 14*, 23–42.
- Weiss, D. S., & Marmar, C. R. (1997). The Impact of Event Scale—Revised. In J. P. Wilson, & T. M. Keane (Eds.), *Assessing psychological trauma and PTSD* (pp. 399–411). New York NY: The Guilford Press.