Changes in Maternal Distress and Child-Rearing Strategies Across Treatment for Pediatric Cancer

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Objectives To examine longitudinal changes in perceived stress, affective distress, and self-reported parenting strategies among mothers of children with cancer over the initial 6 months of diagnosis and treatment, and to examine relationships between changes in distress and subsequent parenting strategies.

Method Questionnaire data were gathered regarding parental perceived stress, caregiver burden, affective distress, and parenting strategies from 65 mothers of children (mean age = 8.3 years) with cancer at 2–5, 12–14, and 22–24 weeks post-diagnosis.

Results Consistent with other studies in the literature, maternal affective distress decreased over the time course of the study. Perceived stress also decreased, while caregiver burden remained relatively stable. Parental consistency fluctuated over the study period, while other parenting strategies (i.e., control, nurturance, and responsiveness) remained stable.

Conclusions Although maternal affective distress decreased following the initial diagnosis of cancer, sources of stress (e.g., caregiver burden) may remain stable, indicating the need for interventions to bolster parental coping resources.

Key words pediatric cancer; parenting behavior; maternal distress; perceived stress; treatment-related stress.

Despite greatly improved outcomes due to medical advances over the past three decades, children with cancer and their parents continue to experience significant distress throughout the course of diagnosis and illness, and beyond. One question that the pediatric psychology literature has begun to address involves the experience, duration, and consequences of parental distress during the child’s course of active therapy.

Several investigations have examined self-reported parental distress immediately or soon after the child’s diagnosis of cancer, with follow-up assessments ranging from 6 to 20 months postdiagnosis (e.g., Dahlquist, Czyzewski, & Jones, 1996; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Manne et al., 1996; Sawyer, Antoniou, Toogood, Rice, & Baghurst, 1993; Sloper, 2000). Some of these studies have indicated high symptomatic levels of distress during the initial weeks (e.g., 2–8) of treatment, with declining levels of distress as treatment progresses (e.g., 12–20 months postdiagnosis). Other investigations, however, have suggested that parental post-diagnosis distress remains stable or evidences only modest decreases over the course of therapy (e.g., 3–6 months, 6–18 months).

Perhaps of greater importance than the duration of elevated distress among parents of children with cancer is whether, and how, such elevations are associated with clinical or psychosocial outcomes for the child and her or his family. For example, several qualitative investigations of families impacted by pediatric cancer suggest that parents may be especially concerned about role strain during active treatment (e.g., Enskar, Carlsson, Golsater, Hamrin, & Kreuger, 1997; McGrath, 2001). Specifically, results of these studies suggest that parents were concerned about the impact of cancer diagnosis and treatment on their parenting behavior. In fact, a number of investigations using quantitative self-report measures have provided some support for these concerns. At assessments ranging in time from one month to more than 7 years post diag-
nosis, parents of children with cancer or other illnesses indicated that they were more lax, more overprotective, and less emotionally responsive to their children than were parents of healthy children (e.g., Davies, Noll, DeStefano, Bukowski, & Kulkarni, 1991; Hillman, 1997; Levers, Drotar, Dahms, Doershuk, & Stern, 1994).

The present investigation was designed to examine the natural history of maternal distress in the weeks following a diagnosis of pediatric cancer, and the relationship of this distress to self-reported parenting strategies. To accomplish this, we first examined three indices of mother-reported distress, corresponding to affective distress (i.e., mood disturbance), perceived stress, and caregiver burden among parents of children with cancer over three assessment points. Consistent with previous research, we hypothesized that each domain of distress (i.e., stress, caregiver burden, and affective distress) would decrease from the initial assessment period as parents adapted to their child’s treatment.

Based on the larger literature on parenting and distress (e.g., Kotchick et al., 1997; Simons, Beaman, Conger, & Chao, 1993), we examined two additional hypotheses. Specifically, we examined changes in mother-reported parenting strategies over the initial phases of therapy among children who were undergoing treatment for cancer. We hypothesized that mothers would endorse more effective parenting strategies (e.g., increased control, consistency, responsiveness, nurturance) at assessments further from diagnosis, that is, at Time 2 (12–14 weeks postdiagnosis) and Time 3 (24–26 weeks postdiagnosis).

Finally, we examined the correlation between changes in maternal distress and subsequent parenting strategies. We hypothesized that increased distress from Time 1 (2–5 weeks postdiagnosis) to Time 2 and from Time 1 to Time 3 would be associated with lower consistency, control, responsiveness, and nurturance at Times 2 and 3, respectively.

**Method**

**Participants**

Seventy-one patients and their mothers who had been admitted to a large children’s research hospital serving children with catastrophic illnesses were approached for possible participation in the study. Of the 71 parent-child dyads that were approached, 68 agreed to participate and provided informed consent/assent according to institutional guidelines. Of the 68 families that completed the initial (Time 1) battery, follow-up questionnaires at Time 2 and Time 3 were received from 65 (96%) of the recruited participants. Of the 3 families that did not complete follow-up measures, one child had died and two children were medically unstable. Because the small number of Hispanic participants (n = 1) would preclude meaningful analysis or generalization to this group, analyses were conducted on data obtained from only African American and white participants. Thus, the final sample size for this report was 64 mother-child dyads. Mean ages of participants and children, as well as other demographic characteristics of the sample, are presented in Table I.

**Measure**

**Perceived Stress.** Two indices of parental stress were used in the present investigation. The Perceived Stress Inventory (PSI; Cohen, Kamarck, & Mermelstein, 1983) is a 14-item self-report inventory designed to assess the degree to which respondents find their lives “unpredictable, uncontrollable, and overloading” (p. 387). Internal consis-

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**Table I. Demographic Characteristics of the Sample**

| Age of caregiver, mean years (SD) | 35.52 (7.8) |
| Age of child, mean years (SD) | 8.27 (2.9) |
| Time since diagnosis, mean days (SD) (Time 1) | 24.91 (9.2) |
| Number of children in the home, mean (SD) | 2.39 (1.1) |
| Sex, % | | |
| Female | 57.4 |
| Race, %a | | |
| White | 72.1 |
| African American | 26.5 |
| Hispanic | 1.5 |
| Marital Status, %a | | |
| Single | 1.5 |
| Marriedb | 88.1 |
| Divorced | 1.5 |
| Widowed | 8.8 |
| Hollingshead socioeconomic categories; c, % | | |
| I | 10.6 |
| II | 45.5 |
| III | 22.7 |
| IV | 10.6 |
| V | 10.6 |
| Diagnostic group, %a | | |
| Leukemia (e.g., ALL, AML) | 53.8 |
| Lymphomas/Hodgkin’s Disease | 9.2 |
| Solid tumors | 16.9 |
| Central nervous system malignancies | 16.9 |
| Other malignancies | 3.1 |

ALL = acute lymphoblastic leukemia; AML = acute myeloid leukemia.

aNumbers may not add to 100 due to rounding.

bIncludes participants who endorsed “Married” or “Living as married” on the demographic sheet.

cHollingshead (1975) categories include: I. major business or professional; II. medium business, minor professional, technical; III. skilled craftsperson, clerical, salesperson; IV. machine operator, semiskilled worker; V. unskilled laborer, service worker, unemployed.
tency of the PSI within the present sample ranged from .87 to .90 across assessments. The PSI includes items such as “In the past two weeks, how often have you felt nervous and stressed?”

The Caregiver Burden Scale (CBS; Poulshock & Deimling, 1984) was administered to parents as an index of the degree to which their role as caregiver was a source of stress. This 14-item, one-dimensional instrument measures the burden a parent experiences in caring for the patient (e.g., “Over the past week, how often have you worried about the patient’s future?”). Internal consistency for the present sample ranged from .83 to .88 across assessments.

Affective Distress. Affective distress was assessed with a short form of the Profile of Mood States (POMS; McNair, Lorr, & Droppelman, 1971), a widely used self-report instrument whose reliability and validity are firmly established. We used a 15-item short form that we felt best captured the range of negative mood states likely for parents in this setting (e.g., tense, sad, confused). Internal consistency for the present sample ranged from .88 to .93 across assessments.

Parenting Strategies. Self-reported parenting strategies were assessed using four subscales (control, consistency, nurturance, and responsiveness) from the Parenting Dimensions Inventory (PDI; Power, 1993). Internal consistency for the subscales selected for this investigation range from .54 (responsiveness) to .82 (consistency; Slater & Power, 1987).

Procedure

Eligibility was based on the following criteria: The patient was newly diagnosed (2–5 weeks) with any malignancy, had no diagnosed physical handicap, was between 4 and 13 years of age, used English as her/his primary language, and was medically stable. Based on these criteria, potential participants were identified from consecutive new admissions to the hospital and were contacted by a research assistant at a clinic visit or in their hospital room between 2 and 5 weeks postdiagnosis. At this initial contact, the research assistant explained the study and obtained informed consent from the parent according to institutional guidelines.

Questionnaires were distributed in person during the initial contact and again approximately 3 months later (12–14 weeks postdiagnosis), with the final set to follow in another 3 months (24–26 weeks postdiagnosis). If the participant was not in the hospital or scheduled to be in the hospital at the time follow-up questionnaires were due, the questionnaires were distributed by mail and were accompanied by a postage-paid return envelope. Mothers who did not return questionnaires within 2 weeks were contacted by phone as a reminder, then, if necessary, were sent a letter and an additional set of questionnaires 2 weeks after the phone call.

Results

Means and standard deviations for the study variables for each of the three assessments are presented in Table II. Preliminary correlational analyses indicated that illness group, race, number of children in the home, and gender of the patient were not significantly correlated with measures of maternal distress or self-reported parenting behaviors, except for a modest correlation between gender and mother-reported nurturance at Time 1 (r = .25, p < .05). This correlation indicated increased self-reported nurturance by mothers of girls at the first assessment. Preliminary analyses of variance (ANOVAs) also indicated that parenting strategies did not differ by marital status. Based on these preliminary results, only gender was retained as a between-subjects variable for all repeated-measures ANOVAs, with assessments at Times 1, 2, and 3 serving as the within-subjects factors.

Changes in Parental Stress/Distress Across Time

To examine within-subjects change in maternal distress across time, three separate repeated-measures ANOVAs were conducted on the measures of stress (i.e., CBS, PSI) and symptoms of distress (i.e., POMS), with gender of the participants included as a between-subjects factor.

Perceived Stress. Results of the repeated-measures ANOVA performed on the PSI indicated a significant within-subjects main effect, F(2, 61) = 5.01, p < .01, with PSI scores at Time 2 and Time 3 significantly lower than Time 1 (p < .05, in both cases). PSI scores at Time 2 and Time 3 were not significantly different from one another.
Symptoms of Affective Distress. Likewise, the results of the repeated-measures ANOVA performed on the POMS indicated a significant within-subjects main effect, $F(2, 61) = 7.63, p < .01$. Pairwise comparisons indicated significantly lower POMS scores (i.e., lower distress) at Times 2 and 3 ($p < .01$, in both cases). POMS scores at Times 2 and 3 were not significantly different from one another.

Caregiver Burden Scale. Results of the repeated-measures ANOVA conducted on the CBS indicated no significant within-subjects effects across the three assessments, $F(2, 61) = 2.02, ns$. No between-subjects differences (gender) or interaction effects were evident.

Changes in Self-Reported Parenting Behavior Across Time

To examine changes in self-reported parenting behavior across time, the four subscale scores from the PDI were subjected to four separate repeated-measures ANOVAs, with child’s gender entered as a between-subjects variable. Results of the repeated-measures ANOVAs performed on the control, responsiveness, and nurturance subscales of the PDI failed to yield significant within-subjects effects. There were no significant gender main effects or gender by within-subjects effects for these three factors of the PDI.

Results of the repeated-measures ANOVA conducted on the consistency subscale of the PDI indicated differences in parent-reported consistency across assessments, $F(2, 61) = 3.31, p < .05$. Specifically, pairwise comparison (least significant difference) of means across the three assessments indicated decreased consistency at Time 3 as compared with Time 2 ($p < .05$).

Correlations Between Distress and Parenting Behavior

To test our third hypothesis, we examined the relationship between changes in distress from Time 1 to Time 2 (i.e., Time 2 distress minus Time 1 distress) and scores on the PDI at Time 2, and changes in distress from Time 1 to Time 3 and scores on the PDI at Time 3. Difference scores were constructed such that higher scores indicated increased distress, while lower scores indicated decreased distress.

Results of the correlational analyses indicated that changes in the measures of distress from Time 1 to Time 2 were not significantly associated with PDI subscale scores at Time 2. However, changes in the CBS from Time 1 to Time 3 were associated with mother-reported parental control at Time 3 ($r = .28, p < .05$). Specifically, higher caregiver burden was associated with higher mother-reported control. Further, changes on the POMS from Time 1 to Time 3 were associated with mother-reported responsiveness ($r = .29, p < .05$). Increased mother-reported symptoms on the POMS were associated with higher responsiveness scores on the PDI.

Discussion

The present investigation examined self-reported affective distress, perceived stress, and caregiver burden among a sample of mothers of children undergoing treatment for cancer. The incorporation of these three measures of distress expands the literature to include not only measures of psychological symptoms (i.e., anxiety and depression), but also indices of sources of stress (i.e., perceptions of events that exceed available resources). We feel that this is consistent with traditional conceptualizations of stress and coping, as outlined by Folkman and Lazarus (1980).

With regard to changes in parental distress over time, our results are similar to previous reports in the literature: Scores on the self-reported measure of affective distress (the POMS) diminished from Time 1 to Time 2 and remained lower at Time 3. This finding is consistent with the relatively brief period of elevated parental distress following a child’s diagnosis of cancer reported in the literature (e.g., Dahlquist et al., 1996).

Our two measures of stress (the PSI and the CBS) yielded mixed results. Consistent with our measure of affective distress, our measure of perceived stress demonstrated a significant decrease from Time 1 to Time 2 and remained at about the same level for Time 3. Our measure of caregiver burden demonstrated no significant decrease over the three assessments. These findings suggest that the initial diagnosis and adjustment to treatment may represent significant challenges to the coping resources of parents but that parents demonstrate resilience (e.g., lower affective distress and perceived stress) in the face of relatively stable levels of caregiver burden.

The second purpose of this investigation was to examine changes in self-reported parenting behaviors over the initial months of diagnosis and treatment. Although some studies have reported differences between parents of children with illnesses and parents of healthy children, no studies to date have examined longitudinal changes in parenting following the diagnosis of pediatric cancer. Our analyses yielded only modest changes in self-reported indices of parenting behavior as measured by the PDI (i.e., increased consistency at approximately 12–14 weeks post-diagnosis). We expect that this finding of increased consistency may reflect parental adaptation to the demands and uncertainty of the initial phases of treatment. That is, parents may learn to be more consistent with their chil-
dren during the initial phases of treatment, when adherence to medical procedures is necessary for the child’s survival.

The third purpose of this investigation was to examine the relationship between changes in maternal stress/distress and parenting behaviors. Results indicated few consistent relationships between self-reported distress and self-reported parenting behaviors. Contrary to our hypotheses, a positive correlation between caregiver burden and parenting control was identified. One explanation for this finding may be that increased parental control is an adaptive response to increased caregiver burden. That is, mothers who experience more burden may exert or value increased parental control in an attempt to maximize available coping resources.

In addition, correlational analyses revealed a positive relationship between changes in affective distress and parental responsiveness. It may be that heightened maternal distress increased self-reported sensitivity to the child’s distress. However, as a self-report instrument, the PDI may be more sensitive to parental values than to routine parental behaviors—this may be especially likely with heightened distress.

Some limitations of this investigation deserve attention and represent areas for further research. First, as noted above, our measures consisted of self-reported indices of maternal affective distress, stress, and parenting behaviors. While this may have exposed our data to increased risk of common method variance, the fact that few significant relationships were found between the measures suggests that the constructs were, in fact, independent. Still, further research using behavioral observations of parent-child interactions may strengthen the conclusions that may be drawn. The use of observational data would also allow for differentiation between parenting values (which may be more resistant to change) and parenting behaviors. It is to be noted that we have identified no studies that used behavioral measures to examine changes in parenting practices following the diagnosis of pediatric cancer. We suggest this as a priority in future psychosocial research among families impacted by pediatric cancer.

Second, our results were obtained from a sample of children with cancer, limiting the extent to which our findings can be generalized to children with other illnesses. While it is interesting that parental distress or parenting strategies did not vary by type of malignancy (e.g., solid tumor vs. leukemia), this should not be taken to suggest that mothers of children with other chronic illnesses would respond in a similar fashion.

Finally, the majority of mothers in the present investigation reported having a domestic partner (i.e., “married or living as married”) and being within the highest three Hollingshead (1975) socioeconomic strata. The degree to which results generalize to single parents or those from lower economic strata is not known. We would expect that single parents and those with lower incomes experience increased burden and distress, and that such distress would negatively impact parenting practices. This remains to be empirically examined.

Despite these limitations, the current investigation fills a gap in the existing literature on parenting and stress among families impacted by the diagnosis and treatment of pediatric cancer. Of particular note, we utilized independent measures of affective distress (i.e., symptoms) and stress (i.e., conditions that are taxing or that exceed coping resources). Our results replicate previously reported findings of decreased mother-reported affective distress in the weeks following the diagnosis of cancer in a child. The present results suggest that the decrease in affective distress occurs soon after diagnosis (i.e., by 12–14 weeks postdiagnosis), and are thus consistent with findings of Dahlquist et al. (1996) and Sawyer et al. (1993).

However, our results also address changes in perceived stress over time. Given that symptoms of distress may result from perceived stress, understanding the sources of stress among families of children with cancer has significant clinical implications. Unlike symptoms of distress, subjective reports suggest that caregiver burden (i.e., a source of stress) among mothers of children with cancer remains relatively stable over the 6 months following diagnosis.

Our results suggest generally stable parenting behaviors in the weeks immediately postdiagnosis, with the exception of changes in mother-reported consistency during the early phases of treatment. This change in consistency may reflect adaptation to the demands of treatment. That is, aspects of treatment of pediatric cancer (e.g., adherence to medications and procedures) may impact mothers’ general beliefs and expectations about consistency. If this is the case, parenting values (perhaps such as those measured in this investigation) as well as parenting behaviors potentially will be impacted. Further investigation of these changes using behavioral observation techniques may be necessary to clarify changes in postdiagnosis parenting among families impacted by pediatric cancer.

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