Patterns of Maternal Distress Among Children With Cancer and Their Association With Child Emotional and Somatic Distress

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Objective To identify patterns of distress among mothers of children with cancer over the initial 6 months of treatment and to examine these patterns as predictors of child somatic and emotional distress. Method Data were gathered regarding maternal perceived stress and affective distress from mothers of children (N = 65, mean age = 8.3 years) with cancer at 2 to 5 weeks postdiagnosis, then at 12 to 14 weeks and 22 to 24 weeks. Mothers and nurses provided indexes of child somatic and emotional distress at these assessments. Results Hierarchical and k-means cluster analyses revealed four distinct patterns of maternal distress: high, moderate, declining, and low. The high maternal distress group reported higher child emotional distress at all three points but higher child somatic distress only at the final assessment. Maternal distress group was unrelated to nurse-reported child distress. Conclusions The identification of four empirically derived patterns of maternal distress may explain some of the variance in the literature regarding parental distress vis-à-vis pediatric cancer treatment and may have relevance to intervention efforts. Differences in the relations between maternal distress groups and mother- and nurse-reported child distress underscore the importance of collecting child distress data from multiple sources.

Key words pediatric cancer; maternal distress; treatment-related distress; cluster analyses.

According to the National Cancer Institute (2002), the current 5-year survival rate for pediatric cancer is approximately 77%, with estimates of 5-year survival rates as high as 90% for some types of cancer (e.g., Hodgkin’s lymphoma). However, despite greatly improved clinical outcomes, children with cancer and their parents continue to experience significant distress throughout the course of their diagnosis and illness. Although research has been conducted to explore family distress during the child’s course of active therapy, several questions regarding the experience of treatment-related distress remain relevant, including the nature, timing, duration, and consequences of the distress.

A number of previous investigations has demonstrated that parents of children with cancer experience elevated levels of distress (e.g., Dahlquist, Czyzewski, & Jones, 1996; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Libov, Nevid, Pelcovitz, & Carmony, 2002). Findings vary based on measurement, but the most commonly identified types of distress have included depression, anxiety, posttraumatic stress symptoms, and subjective symptoms of “stress.” Estimates of moderate to severe symptoms of distress range from 15% to 51% (Manne et al., 1995; Manne et al., 2001; Sloper, 2000), and some research indicates that as many as 95% of families coping with pediatric cancer report some symptoms of distress (e.g., Kazak et al., 2001).

In addition to the nature of distress experienced by families coping with pediatric cancer, variations in the timing and duration of heightened levels of distress have differed in the literature as well. Some studies have found elevated levels near diagnosis with decreasing symptoms over time (Dalquist et al., 1996; Hoekstra-Weebers et al., 2001; Sawyer, Antoniou, Toogood, Rice, 2001). Findings vary based on measurement, but the most commonly identified types of distress have included depression, anxiety, posttraumatic stress symptoms, and subjective symptoms of “stress.” Estimates of moderate to severe symptoms of distress range from 15% to 51% (Manne et al., 1995; Manne et al., 2001; Sloper, 2000), and some research indicates that as many as 95% of families coping with pediatric cancer report some symptoms of distress (e.g., Kazak et al., 2001).
Consequences of parental distress have been examined in the literature as well. Parents are often overwhelmed by the diagnosis of cancer and the intensity of the treatment, which can negatively affect their ability to function as parents and their child's ability to handle the treatment (Manne et al., 1996). Parents who experience high levels of distress may be less able to help their children cope with the intensive treatments required to fight cancer. Research has also found a relationship between parental-child distress and behavior problems among children with cancer and other chronic illnesses (Canning, Hanser, Shade, & Boyce, 1993; Thompson, Gustafson, George, & Spock, 1994). For instance, Manne and colleagues found that child behavior problems were strongly associated with parental depressive symptoms and that parents who maintained moderate-to-severe symptoms of depression reported significantly more child distress than those whose depressive symptoms were mild or had decreased over time (Manne et al., 1995; Manne et al., 1996).

Several hypotheses have been offered to describe the relation between parent and child distress. Some studies have suggested that parental distress affects family functioning (i.e., cohesion, expressiveness), which in turn affects child adjustment (e.g., Conrad & Hamm, 1989; Varni, Katz, Colegrove, & Dolgin, 1996; Williams et al., 1999). This is consistent with previous findings among families coping with a parent's chronic illness (Steele, Forehand, & Armistead, 1997). An alternative hypothesis is that maternal distress leads mothers to inaccurately perceive children's distress and behavior problems (Dumas & Serketich, 1994).

As noted, Manne and colleagues (1995, 1996) reported that children of mothers who experienced increasing or high symptoms of depression over 6 months evidenced more parent-reported distress than mothers who evidenced decreasing or low levels of depression. These investigations were particularly important in that they began to identify patterns of maternal behavior that may have an impact on para- or posttreatment child functioning.

The present investigation builds on Manne and colleagues’ work (1995; 1996) in two important ways. First, using cluster analyses methodology, we empirically derived patterns of maternal distress across three time points over the initial 6 months of treatment for pediatric cancer. Manne and colleagues' findings of differential child-behavior outcomes resulting from different patterns of parental distress suggest that posttreatment child adjustment may be dependent, at least in part, on caregivers’ psychosocial functioning during treatment. However, the literature is inconclusive about which parents are at particular risk for increasing symptoms of distress during their child’s treatment and for how long such symptoms are likely to be elevated. This uncertainty in the literature may adversely affect the degree to which the allocation of limited resources (e.g., intervention) is based on empirical support. Our investigation introduces to the pediatric cancer literature a novel method of identifying patterns of distress that goes beyond simple change scores or dichotomization of maternal distress into high and low groups. Rather, cluster analysis identifies subgroups of individuals that differ in their relative distances from one another on a given set of measures (Hair, Anderson, Tatham, & Black, 1998), perhaps identifying groups that are qualitatively distinct from one another.

Second, toward the goal of identifying parents at particular risk of distress, we examined empirically derived patterns of maternal distress in relation to child somatic and emotional distress. Identification of early predictors of family distress may provide an opportunity for the prevention of parent psychosocial adjustment problems and nascent child behavior problems, and it may also be useful in assessing the appropriateness of interventions among families affected by cancer (e.g., Sahler et al., 2002). The present investigation used nurse reports of child somatic distress, as well as maternal reports of child emotional and somatic distress.

Consistent with previous literature, our hypothesis was that maternal distress would be significantly related to child distress, such that high levels of child distress would be associated with patterns of high or increasing levels of maternal distress. Likewise, we hypothesized that lower levels of child distress would be associated with patterns of low or decreasing levels of maternal distress.

**Method**

**Participants**

Seventy-one (71) patients and their mothers were approached for possible participation in the study, and 68 agreed to participate, resulting in a 95.8% participation rate.
rate. All mothers provided informed consent according to the institutional guidelines at St. Jude Children’s Research Hospital.

Participants were asked to complete the same battery of questionnaires at three points over the course of approximately 6 months. Sixty-eight (68) families completed the initial battery (Time 1, 2–5 weeks post-diagnosis). Of those, 65 (96%) completed the follow-up questionnaires (Time 2, 12–14 weeks postdiagnosis; and Time 3, 22–24 weeks postdiagnosis) Three participants did not complete follow-up measures: 2 participants were not contacted for follow-up because their children were critically ill, and 1 participant was lost due to the death of the child.

Measures

Maternal Distress

This composite consisted of the sum of two measures of maternal distress: perceived stress and affective distress. The Perceived Stress Scale (PSS; Cohen, Kamarck, & Merrelstein, 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). Respondents were specifically instructed to report on their experience of stress over the past week. Internal consistency of the PSS is reportedly good (α = .84–.86; Cohen et al., 1983). Concurrent and predictive validity have been established through significant correlations with number and impact of negative life events, physical symptomatology, health care utilization, and (to a lesser degree) symptoms of affective distress among adult samples (e.g., depression, social anxiety; Cohen et al., 1983). Internal consistency of the PSS within the present sample was .88. Higher scores indicate higher levels of perceived stress.

Affective distress was assessed with a short form of the Profile of Mood States (McNair, Loor, & Droppleman, 1971), a widely used self-report instrument whose reliability and validity is firmly established. Respondents rated the degree to which they experienced different emotional states over the past week (e.g., energetic, tense, hopeless). Several short forms have been shown to correlate highly with the Total Mood Disturbance scale of the full measure (Cella et al., 1987; Shacham, 1983). This study used a 15-item form that the authors believed best captured the range of negative mood states likely for mothers in this setting. Internal consistency for the present sample was .88. Higher scores are associated with increased affective distress.

Child Distress

The level of children’s emotional distress (i.e., mood and behavior problems) and somatic distress were measured by the Mood/Behavior and Somatic Distress subscales of the Behavioral, Affective, and Somatic Experiences Scale (BASES; Phipps, Hinds, Channell, & Bell, 1994). The child’s mother completed both subscales of the BASES, and a member of the nursing staff, who cared for the child on the day of the assessment, completed the Somatic Distress subscale. The Somatic Distress subscale of the BASES consists of 10 unpleasant symptoms (e.g., fever/chills, mucositis) experienced by many children undergoing treatment for cancer. Items are rated on a 5-point Likert-type scale with endpoints of 1 (none/not present) to 5 (severe). Consistent with Phipps et al. (1994), items on the parent version of the BASES were reworded for clarity (e.g., mouth sores substituted for mucositis). Mothers were instructed to report on their child’s apparent distress related to the 10 specific symptoms over the past week, whereas nurses reported on the child’s somatic distress based on observations made during a single day or shift. Consistent with mothers, nurses rated the children’s apparent distress per the 10 specific symptoms on the BASES.

The Mood/Behavior subscale of the BASES consists of 14 moods or behaviors (positive and negative) that might be displayed by a child undergoing treatment for cancer (e.g., cheerful/friendly, sad/subdued). A rater responds on a 5-point Likert-type scale with endpoints of 1 (very much like this) to 5 (very much unlike this). Negatively worded items (e.g., fearful/anxious) were reverse scored such that higher scores indicated increased mood or behavior problems. Phipps et al. (1994) reported good internal consistency for the BASES subscales (.74–.90) and that the median correlation between pairs of nurse observations was .87, indicating very high interrater agreement across different nurse reporters.

Internal consistency for the present sample was .59 and .84 (for the nurse and parent reports on the Somatic Distress subscale, respectively) and .88 (for the parent-reported Mood/Behavior subscale). Items were scored such that increasing values were associated with increased distress.

Procedure

Participants were recruited from among consecutive new admissions to a large children’s research hospital whose primary mission is to serve children with catastrophic illnesses (e.g., cancer, HIV infection). The hospital accepts patients nationally and internationally who
are referred by primary care physicians and pediatric illness specialists. All procedures described in this report were approved by the institution's human subjects committee.

All new admissions were screened for eligibility based on the following criteria:

1. the patient was newly diagnosed (2–5 weeks) with any malignancy;
2. the patient had no diagnosed developmental delay;
3. the patient had no significant physical handicap necessitating altered parental child-rearing behaviors;
4. the patient was between 4 and 13 years of age;
5. the patient used English as his or her primary language; and
6. the patient was medically stable as determined by his or her primary physician.

Mothers’ data (as opposed to that of other family members) were obtained for conceptual as well as practical reasons. First, as noted by Manne and colleagues (2001), mothers of children with cancer typically bear the brunt of caregiving responsibilities and are at particular risk (relative to other family members) of negative psychosocial adjustment during and after a child's diagnosis and treatment. At a more practical level, mothers were chosen for participation because of the relative infrequency with which fathers were present in the hospital on a day-to-day basis. Adolescents were excluded from participation because of the qualitatively different relationship that they have with their parents, compared to that between children and parents.

Based on these eligibility criteria, a research assistant identified potential participants from consecutive new admissions to the hospital and contacted them at a clinic visit or, in the case of inpatients, in their hospital room between 2 and 5 weeks postdiagnosis. The average time between diagnosis and initial contact with the family was 24.9 days ($SD = 9.2$). At the initial contact the research assistant explained the study and obtained informed consent from the parent according to institutional guidelines. Parents consented to completing a set of questionnaires during the clinic visit or hospitalization. Clinic or floor nurses were asked to complete measures of child distress at the same time as parents completed their questionnaire packets. Although it is not unusual for children to be treated by the same nurse across visits, data collection for this study did not include information regarding which nurses completed BASES for which participants.

Additional assessments were conducted approximately 3 and 6 months later. If the participant was not in the hospital or scheduled to come in for treatment, questionnaires were mailed to the participant, with a postage-paid return envelope. Parents who did not return questionnaires within 2 weeks were contacted by phone for a reminder. If questionnaires had still not been received, a second set of questionnaires was mailed approximately 2 weeks later, accompanied by a reminder letter. The mean period between diagnosis and Time 2 assessment was 88.6 days ($SD = 34.1$), while the mean period between diagnosis and Time 3 assessment was 179.7 days ($SD = 54.7$).

Results
Overview of Analyses

Descriptive statistics were first conducted to characterize the sample, after which cluster analyses were conducted to examine patterns of maternal distress at 2 to 5 weeks postdiagnosis, then at 10 to 12 weeks and 22 to 24 weeks. As described by Taylor et al. (2001), cluster analysis is an exploratory statistical method that is used to identify natural groups or patterns of responses on a given set of measures. Individuals are empirically sorted into groups by the relative distances from one another on a given set of measures (Hair et al., 1998). Cluster analysis is often used as a means of describing change across time (Burgess et al., 2002) or of identifying patterns of adjustment within samples (Grych, Jouriles, Swank, McDonald, & Norwood, 2000). Similar to the procedure used by Taylor et al. (2001), the plan we employed involved a two-phased cluster analysis to examine change in maternal distress across the three noted assessments.

First, to provide the maximum flexibility in determining the appropriate number of factors, we examined the standardized ($z$ score) data using a hierarchical cluster analysis method (i.e., Ward’s method and squared Euclidean distance). This process allowed us to identify the number of clusters that maximizes differences between clusters or groups on the dependent variable (i.e., maternal distress). We then used a nonhierarchical cluster analysis ($k$ means) to confirm the number of clusters identified by Ward’s method. As described by Taylor et al. (2001), this method provides a relatively robust identification of clinically meaningful clusters of participants. Cluster membership was retained as an independent variable and was used as a predictor of nurse-reported child distress at each of the postdiagnosis assessment points.
Patterns of Maternal Distress

Descriptive Statistics

Mean ages of participants and children, as well as other demographic characteristics of the sample are presented in Table I.

Consistent with the demographics of the pediatric cancer population of the hospital, the majority of children (54%) were being treated for some form of leukemia (primarily ALL and AML). Because the treatment and prognoses for different forms of leukemia often differ, we examined differences in parent and child distress and demographic characteristics across more homogeneous diagnostic groupings (e.g., ALL vs. AML vs. other leukemia). No significant differences emerged. We thus used leukemia as a grouping variable to preserve power to detect differences. Participants described themselves as African American (26.5%), Caucasian (72%), or Hispanic (1.5%). Means and standard deviations for the measures of parent and child distress at all three assessments can be found in Table II.

Table I. Demographic Characteristics of the Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>M (SD)</th>
<th>Frequency (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of caregiver</td>
<td>35.52 (7.8)</td>
<td></td>
</tr>
<tr>
<td>Age of child</td>
<td>8.27 (2.9)</td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis in days (Time 1)</td>
<td>24.91 (9.2)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>57.4</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>26.5</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>72.1</td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
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<tr>
<td>Single</td>
<td>1.5</td>
<td></td>
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<tr>
<td>Married*a</td>
<td>86.1</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>1.5</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>8.8</td>
<td></td>
</tr>
<tr>
<td>Hollingshead SES Indexb</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I: Major business or professional</td>
<td>10.6</td>
<td></td>
</tr>
<tr>
<td>II: Medium business, minor professional, technical</td>
<td>45.5</td>
<td></td>
</tr>
<tr>
<td>III: Skilled craftsperson, clerical, salesperson</td>
<td>22.7</td>
<td></td>
</tr>
<tr>
<td>IV: Machine operator, semiskilled worker</td>
<td>10.6</td>
<td></td>
</tr>
<tr>
<td>V: Unskilled laborers, service workers, unemployed</td>
<td>10.6</td>
<td></td>
</tr>
<tr>
<td>Diagnostic group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leukemia (e.g., ALL, AML)</td>
<td>53.8</td>
<td></td>
</tr>
<tr>
<td>Lymphomas/Hodgkin’s disease</td>
<td>9.2</td>
<td></td>
</tr>
<tr>
<td>Solid tumors</td>
<td>16.9</td>
<td></td>
</tr>
<tr>
<td>Central nervous system malignancies</td>
<td>16.9</td>
<td></td>
</tr>
<tr>
<td>Other malignancies</td>
<td>3.1</td>
<td></td>
</tr>
</tbody>
</table>

*a*Includes participants who endorsed “married” or “living as married” on the demographic sheet.

*b*Based on Hollingshead (1975).

Preliminary analyses were conducted to determine whether maternal distress varied by the child’s diagnosis, race, gender, or by the mother’s marital status or the family’s socioeconomic grouping (Hollingshead, 1975). Maternal distress did not vary by diagnostic group, race, gender, or socioeconomic or marital status.

Cluster Analyses

In a manner consistent with the methodology employed in the adult clinical literature (e.g., Burns, Kubilus, Bruehl, & Harden, 2001), standardized (z score) measures of maternal reports of distress were subjected to hierarchical cluster analyses (Ward’s method), using squared Euclidean distances to derive cluster centers. Percentage of change in the agglomeration coefficient (i.e., within clusters sum of squares) from stage to stage was examined to determine the most appropriate number of clusters. Small incremental change suggests that relatively homogeneous clusters were combined in the previous step, whereas larger change suggests that relatively heterogeneous clusters were combined (Hair et al., 1998).

As demonstrated in Table III, relatively trivial changes in the agglomeration coefficient were observed until the stage in which four clusters were reduced to three. The large increase in the agglomeration coefficient (45.9%) at that point suggested that two very distinct clusters had been combined.

We thus performed a MANOVA with the mean scores of maternal distress for the four clusters across...
As expected, the overall MANOVA was significant, Wilks’s $\lambda = .099$, $F(9, 144) = 25.42$, $p < .001$, and results indicated significant differences in maternal distress at all three time points, Time 1, $F(3, 64) = 87.561$, $p < .001$; Time 2, $F(3, 64) = 38.705$, $p < .001$; Time 3, $F(3, 64) = 50.509$, $p < .001$. Cluster means for maternal distress across the three assessments are presented in Table IV.

Finally, to confirm the cluster groupings, the standardized data were submitted to $k$-means cluster analysis, with four clusters specified. Visual inspection of the means suggested similar cluster centers. Overall, 45 out of 65 cases (69.2%) were classified into the same clusters by the Ward and $k$-means methods, with individual cluster agreement ranging from 41% (Cluster 2) to 90% (Cluster 1). Corresponding to the patterns demonstrated in Figure 1, groups were identified as high ($n = 9$, 13.2%), moderate ($n = 17$, 25%), declining ($n = 21$, 31%), and low ($n = 18$, 27%) distress. Consistent with the preliminary data (above), these patterns of distress were not significantly associated with diagnostic category, race, gender, or SES.

**Cluster Grouping as a Predictor of Child Distress**

Cluster group membership using the four-cluster solution was retained as an independent variable to examine the relation between patterns of maternal distress and child emotional and somatic distress. Because the ratings of distress across the three time points were expected to be correlated, independent $4 \times 3$ (distress group) MANOVAs were conducted for each of the three measures of distress (mother-reported somatic and emotional distress, and nurse-reported somatic distress). Results indicated that maternal cluster membership was significantly associated with mother-reported child emotional distress, Wilks’s $\lambda = .72$, $F(9, 144) = 2.31$, $p < .05$, with significant differences...
across all three time points, Time 1, $F(3, 64) = 4.42, p < .01$; Time 2, $F(3, 64) = 4.46, p < .01$; Time 3, $F(3, 64) = 4.88, p < .01$. That is, at all three assessments, there were statistically significant differences in mother-reported child distress across the four cluster groups. Similarly, results indicated that mothers’ pattern of distress was associated with mother-reported somatic distress, Wilks’s $\lambda = .75$, $F(9, 144) = 1.98, p < .05$, but only at the third assessment (22–24 weeks), $F(3, 64) = 3.55, p < .05$. In other words, at the third assessment, mean levels of mother-reported somatic distress differed across the four cluster groups. Finally, results indicated that mothers’ pattern of self-reported distress was not significantly associated with nurse-reported child somatic distress, Wilks’s $\lambda = .85$, $F(9, 115) = .88, ns$. Group means for each of the measures at each of the assessments are presented in Table IV.

Post hoc analyses for mother-reported child emotional distress suggest that children of mothers in the high distress group were more distressed than children of mothers in the declining ($p < .01$) and low distress groups ($p < .01$) but not more distressed than children of mothers in the moderately distressed group. The declining and low groups did not differ on maternal reports of child emotional distress. Similarly, children of mothers in the high distress group had more mother-reported somatic distress than children in the moderate ($p < .05$) or low ($p < .005$) groups but not more than children of mothers in the declining group. Unexpectedly, the mothers in the declining distress group reported that their children experienced more somatic distress than children in the low maternal distress group ($p < .05$).

Further post hoc analyses were conducted to examine differences in parent and nurse reports of child somatic distress. A series of paired-sample $t$ tests indicated that only at Time 1 did nurse and parent report of distress differ significantly—perhaps as expected, with nurses indicating lower child-somatic distress than what parents reported, $t(61) = -4.59, p < .001$. At the second and third assessments, parents and nurses did not report child somatic distress significantly different. Three 1-way ANOVAs indicated that nurse–parent discrepancy with regard to child somatic distress did not differ by cluster group membership, and correlational analyses did not reveal significant relationships between discrepancy (between reporters) and child emotional functioning.

**Discussion**

The present investigation was designed around two purposes. First, we sought to empirically derive clusters, or patterns, of maternal distress among families coping with the diagnosis and treatment of pediatric cancer. Second, we attempted to validate these clusters by demonstrating an association between patterns of maternal distress and child distress using mother-reported and nurse-reported measures of child distress. The addition of nurse-reported distress represents an advance in the literature, as previous investigations have primarily used parent reports for parent and child adjustment.
With regard to our first goal, our results were similar to those reported by Manne and colleagues (1995; 1996), in that we identified four distinct patterns of maternal distress. However, several differences should be noted. First, our patterns of maternal distress were derived from a composite of two robust measures of distress, which may have allowed the detection of more subtle patterns than previously identified. Second, rather than the use of an a priori cutoff score to assign mothers’ group membership (e.g., a BDI score greater than or less than 15), we used hierarchical and k-means cluster analyses to identify the most statistically unique maternal distress groups.

While the groups identified using this methodology were not particularly complex (high, moderate, declining, and low), their presence does suggest a possible explanation for at least some of the variance observed in the literature regarding the duration and timing of heightened family distress over the course of treatment for cancer (e.g., Sloper, 2000; Steele et al., 2003). Rather than a single pattern of heightened distress at a given point post-diagnosis, we find it more plausible that multiple patterns of stress and coping exist, as suggested by our results.

At a practical level, these results suggest that not all parents (i.e., not all mothers) are at equal risk for the development of symptoms of distress that warrant intervention. Further, our results indicate that these patterns do not covary with major diagnostic groups. These results speak to the resilience of many families in the face of the exceedingly complex demands of their child’s diagnosis and treatment. Alternatively, some families may evidence heightened distress even with appropriate referrals to psychosocial support providers. However, the utilization and influence of available support services (e.g., social work, psychology, pastoral counseling, etc.) is unknown and remains a topic for future investigation.

The second purpose of this study was to examine the empirically derived patterns of maternal distress in association with parent- and nurse-reported child distress. Again, our results are partially consistent with literature regarding similarities in levels of distress between children and their parents (Manne et al., 1995; Manne et al., 1996). Consistent with our hypothesis, the pattern of high maternal distress was associated with higher mother-reported child emotional distress than patterns of declining or low distress at all three time points. It may be worth noting that children of mothers in the declining and low distress clusters had similar reports of emotional distress even while maternal distress was significantly different.

The results regarding mother-reported child somatic distress are somewhat more difficult to interpret. First, it is curious that mother-reported child somatic distress was related to mother distress pattern only at the third assessment. As hypothesized, children of mothers in the high distress group had more mother-reported somatic distress at the final assessment (22–24 weeks) than children in the moderate and low groups. It may be that mothers are initially able to remain more objective regarding the sometimes-inevitable side effects of cancer treatment (e.g., mucositis, nausea) but become emotionally sensitized to these consequences as treatment progresses. This represents an area for further clinical investigation.

A strength of the present investigation was the use of nurse-reported somatic distress as an independent validator of maternal distress clusters. Contrary to our hypotheses, nurse-reported child somatic distress was not associated with maternal distress clusters. There may be several reasons for this null finding. First, it is possible that the relation between maternal distress and mother-reported child distress is primarily a result of common method variance. Few studies in the literature have used independent measures of child distress to ascertain the validity of the reported link between parental and child distress (Canning et al., 1993). However, the differential pattern of results across emotional and somatic distress that we obtained suggests that further work in this area is needed.

A second possible explanation for the null findings regarding nurse-reported child somatic distress is the relatively lower internal consistency ($\alpha = .59$) in nurse-reported child somatic distress. Since the somatic distress scale comprised symptoms that would not necessarily covary (e.g., fatigue, skin problems), a low internal consistency estimate is not surprising, but may have limited our ability to detect a relation between nurse-reported and parent-reported distress.

It is also possible that mothers’ acclimation to the ambient distress of the cancer treatment environment may have affected their subsequent reports of child somatic distress. Our findings regarding differential levels of discrepancy between nurse- and mother-reported child somatic distress (i.e., from initial to subsequent assessments) would seem to be consistent with this idea. As we have commented elsewhere (Johnston, Steele, Herrera, & Phipps, 2003), the association between reporter discrepancy and child functioning may be an area deserving of further research.

Since maternal distress clusters were not associated with the child's diagnosis, length of treatment, race,
marital status, or socioeconomic status, one might hypothesize that the lower (or declining) levels of distress are the result of above average (or improving) coping strategies. If our identified clusters are confirmed by additional research, investigations of coping techniques among high functioning families may be warranted. Again, more information regarding the psychosocial or mental health resources utilized might be of benefit in identifying sources of strength among these families.

A number of limitations should be noted. Foremost among them is the possibility of common method variance effects in our results. As described, the discrepancies between maternal distress cluster and nurse- and parent-reported child distress suggests the need for more studies with independent reports of child distress. Further, we note that the number of participants in each cluster group is relatively small, which may have limited our power to detect differences across these empirically derived groups. We also note the correlational nature of the investigation, which prohibits any causal inferences of directional associations between parent and child distress.

Our results may also be somewhat limited by the demographic characteristics of the sample. As indicated in Table I, the sample was composed of predominantly Caucasian, middle-class, partnered (i.e., married or living as married) families. Thus, it is not clear how these results generalize to people with fewer social and environmental resources. The results are also limited by timing of assessments. Although we view the examination of families’ adjustment immediately postdiagnosis as extremely valuable, our data did not let us examine the more proximal adjustment to the end of treatment and recovery.

Finally, although patterns of maternal distress did not vary by child diagnostic group, our results are limited to children with cancer and may not generalize to other illness groups. Further, our data did not allow for examination of distress relative to disease-specific risk within or across diagnostic groups (e.g., Stage 1 vs. Stage 4 solid tumor). This may provide a more fine-grained approach to predicting and understanding distress among families affected by pediatric cancer and should be considered in future studies.

In sum, we identified four distinct patterns of maternal distress that appear related to mothers’ reports of child emotional and somatic distress. Many questions remain unanswered, including the generalizability of the patterns of distress to other samples, the relation of defensive responding to patterns of distress, and the relation of patterns of distress to more objective reports of child distress. Nevertheless, results provide a starting point for more fine-grained analyses (i.e., using cluster analysis) of families’ responses to the initial treatment of children diagnosed with cancer. Further, the failure of our data to demonstrate an association between maternal distress and an independent observation of child distress underscores the need for more widespread use of independent observation of child distress in the literature.

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References


Notes

1. Because the relatively smaller sample sizes for these preliminary analyses might severely limit power, we opted for a more liberal $p$ value ($p < .20$) to determine whether different leukemia diagnoses (e.g., ALL vs. AML vs. other leukemia vs. Hodgkin's) were associated with differences in distress. In these analyses, we found no differences for any variables ($ps$ in excess of .50 in all cases). Thus, we retained the diagnostic grouping of leukemia for further analyses.

2. For the total sample, maternal distress and mother-reported child emotional distress were significantly greater at the initial assessment than at the 10–12-week and 22–24-week follow-ups, maternal distress, $\lambda = .78$, $F(2, 63) = 9.13, p < .001$, partial $\eta^2 = .23$; mother-reported child-emotional distress, $\lambda = .76$, $F(2, 63) = 10.12, p < .001$, partial $\eta^2 = .24$. No significant differences across time were observed for mother-reported child somatic distress or nurse-reported somatic distress.