Brief Report

Brief Report: Parenting Stress and Quality of Life During Treatment for Childhood Leukemia Predicts Child and Parent Adjustment After Treatment Ends

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Evaluated relationships between parenting stress and parent-rated child quality of life during treatment for childhood leukemia and later parental posttraumatic stress symptoms and parent and child anxiety after completion of cancer treatment in 29 families of patients with leukemia. Correlations among in-treatment and off-treatment variables showed strong patterns of association between parenting stress during treatment and later parental adjustment, for both mothers and fathers. Parent-rated child quality of life was also significantly associated with later adjustment for mothers and children. Despite the small sample, data point to the importance and consistency of parental reactions from diagnosis through the end of treatment and have clinical implications for psychosocial services during and after treatment.

KEY WORDS: pediatric oncology; parent and child adjustment; predicting psychological outcome; posttraumatic stress.

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The association between distress during treatment for pediatric illness and the long-term adjustment of children and families is of broad interest to healthcare providers, yet little understood. Clinical wisdom underscores the idea that those children and families who are well adjusted at diagnosis will cope most adaptively with the extreme stressors associated with diagnosis and treatment. The landmark longitudinal study of 64 families of children with leukemia conducted by Kupst and Schulman (1988) supports the persistence of “good copers” and family functioning throughout treatment and up to 10 years later in the 28 participants available for the long-term follow up (Kupst et al., 1995).

While these findings are important, they are general in nature, and unlikely to be replicated extensively, given the difficulties of conducting and sustaining longitudinal family research. In the present paper, we report mother and father data on parenting stress and quality of life (QOL) in children with leukemia in a first remission collected in 1991. We compare these data prospectively with parent and child data from the same families who later participated, in 1994-1996, (≥6 months after ending cancer treatment) in a study of psychological sequelae of cancer survival, focused on anxiety and symptoms of posttraumatic stress.

Among the most distressing aspects of childhood leukemia treatment are necessary repeated invasive procedures. Parental distress specific to procedures remained relatively high and constant over the 2 to 3 years of leukemia treatment (Kazak et al., 1995). While the reduction of pain and anxiety during procedures has been a successful area of psychological intervention (Rape & Bush, 1994), procedures continue to be among the most frequently distressing memories reported by survivors and their parents (Kazak, Stuber, Barakat, & Meeske, 1996). Stress specific to parenting is particularly relevant both in treatment and after treatment ends as it captures parent–child interactions in acute situations (e.g., medical procedures) as well as the broader realm of parent–child relationships impacted on by the illness and its treatment. Similarly, the importance attached to evaluations of QOL hinges on its long-term significance for patients and families surviving cancer. While small (n = 29), the present study is unique in providing a prospective link between distress during treatment and long-term adjustment to having had cancer.

The literature on psychological adjustment to childhood cancer survival indicates that most survivors do relatively well, although a subset across a
number of studies evidence more serious adjustment difficulties (Kazak, 1994). Less research on parental adjustment is available although the impact on parents in terms of ongoing worries about their child and more feelings of alienation from others has been reported (Van Dongen-Melman et al., 1995). The concept of posttraumatic stress may be helpful in understanding the long-term psychological reactions of survivors and their parents. Indeed, discussions of trauma in the context of illness have become more prevalent recently, paralleling the inclusion of "learning that one/one's child has a life threatening disease" (p. 424) as a diagnostic criteria for Posttraumatic Stress Disorder (PTSD) in DSM-IV (American Psychiatric Association, 1994). Our research comparing childhood cancer survivors with comparison families has suggested that a disturbing, yet subdiagnostic, cluster of anxiety symptoms affect childhood cancer survivors (Stuber, Christakis, Houskamp, & Kazak, 1996) and, more dramatically, their parents (Kazak, Barakat, et al., 1997). The roots of these later symptoms are associated with child and parent anxiety during treatment (Kazak et al., 1996) although these associations have not been evaluated prospectively, to our knowledge.

We present prospective correlational data, comparing parenting stress and child QOL reported by mothers and fathers of children receiving treatment for leukemia in a first remission with mother, father, and child report of anxiety and posttraumatic stress from these same families after they have completed treatment. It was hypothesized that higher levels of parenting stress and poorer parent-report child QOL during treatment will be associated with increased reports of parental posttraumatic symptoms and parent (mother and father) and child anxiety after treatment ends.

METHOD

Participants

Twenty-nine children and adolescents treated for leukemia, and their parents, at a large urban children's hospital, participated in two separate studies which form the basis of the present report. In the first (in-treatment) study in 1991, the patients were in treatment for leukemia in a first remission. They were part of a larger study of parental perceptions of procedural distress and child adjustment (Kazak et al., 1995). All eligible families from the in-treatment study (n = 51) were among those in a larger off-treatment study sent letters in 1993–1995 regarding a study of psychological sequelae and posttraumatic stress symptoms in childhood cancer survival (Kazak, Barakat, et al., 1997). Of the original sample, 19 were not eligible: 4 were too old, 3 were deceased, 2 had relapsed, and 11 were lost to follow-up. The participation rate was 29/51 (57%). The most frequent reasons for refusal were not wanting to revisit the cancer, or feeling that
it was not relevant for them anymore. There were no significant differences between participants and nonparticipants in the off-treatment study on child age at diagnosis, child age during the in-treatment study, months off treatment, nor with respect to the parenting stress and quality of life variables, from mother and father report.

The age of former patients was 7.64 years ($SD = 3.54$) at the time of the in-treatment study and 9.79 years ($SD = 3.22$) at the time of the off-treatment study. With respect to gender, 55% were girls and 45% boys. The majority (90%) were survivors of ALL and the remaining 10% had been treated for ANLL. The majority of families were two-parent units (80%) and most were Caucasian (97%) with 1 Asian family. Income levels and parental education were consistent with middle-class families in this geographical region, with 50% of the sample reporting total annual household incomes between $50,000-100,000. Approximately one half of parents had college degrees or some graduate training, or advanced degrees.

**Measures**

The first two measures were completed by mothers and fathers during the in-treatment study. The third and fourth were completed by parents as part of the off-treatment study. The final measure was child report, off treatment. To assure anonymity and promote disclosure, family members are asked to complete forms independently and seal them in separate envelopes.

*The Parenting Stress Index-Short Form (PSI)* is a 36-item Likert type questionnaire used widely in pediatric settings (Abidin, 1990) with three subscales (Parental Distress, Parent–Child Dysfunctional Interaction, Difficult Child). Internal consistency (Cronbach’s alphas) ranged from .80 to .91 with test–retest reliabilities for the total score and factors ranging from .68 to .85. Lower scores indicate less stress.

*The Pediatric Oncology Quality of Life Scale (POQOLS)*, a 21-item 7-point Likert type scale, measures frequency of pediatric oncology patients' daily activities over 2 weeks (Goodwin, Boggs, & Graham-Poole, 1994). The POQOLS yielded a total score and three factors: Role restriction and physical functioning, Emotional Distress, and Response to Current Medical Treatment. Internal consistency measured by coefficient alphas yielded reliability scores for the three factors ranging from .68 to .87. Lower scores indicate better QOL.

*The Post Traumatic Stress Reaction Index*, a 20-item self-report questionnaire, assesses symptoms of posttraumatic stress (Pynoos, Frederick, Nader, & Arroyo, 1987), including intrusion, avoidance, and arousal. There are strong associations of Reaction Index scores with diagnoses of Post Traumatic Stress Disorder in adults and children (Pynoos et al., 1993). Scores are categorized:
mild (12–24), moderate (25–39), and severe (>40). Frequency of each item is endorsed on a 4-point scale; the total score was used.

The *State-Trait Anxiety Inventory (STAI)*, a 40-item self-report scale, assesses anxiety symptoms with regard to both current (state) and personality (trait) anxiety (Spielberger, 1983). Test–retest reliability is low for State and high for Trait, as expected. The STAI has high internal consistency and adequate construct and discriminative validity across diverse samples (Novy, Nelson, Goodwin, & Rowzee, 1993). Higher scores indicate higher levels of anxiety. For the current study, we utilized state anxiety to evaluate parents’ current (posttreatment) anxiety, rather than more stable personality attributes.

The *Revised Children’s Manifest Anxiety Scale (RCMAS)* is an established 37-item self-report inventory of trait anxiety in children (Reynolds & Richmond, 1985). Internal consistency, test–retest reliability, and construct and discriminative validity are adequate (Perrin & Last, 1992). The total score (a standardized t score) was utilized with higher scores indicating higher levels of physiological arousal, worry, oversensitivity, and concentration difficulties.

**Procedure**

Both studies were approved by the Institutional Review Board at our institution. The procedure for the two studies was very similar. Packets containing questionnaires, a consent form and postage-paid envelopes were mailed to families. Further details of the procedure and samples are published elsewhere (Kazak, Barakat, et al., 1997; Kazak et al., 1995).

**RESULTS**

Sample means for the in-treatment and off-treatment standardized measures are presented in Table I along with normative data. In general, sample scores were within normal limits for the measures (i.e., within 1 SD of the norm). Elevations on the Reaction Index for both parents are consistent with the findings of the larger survivor study (Kazak, Barakat, et al., 1997). Our sample’s scores indicated significantly higher QOL than normative sample for the POQOLS and, for fathers, higher stress on the PSI. Although not a hypothesis of the study, t tests were conducted, using sample means and standard deviations and normative data. The higher levels of quality of life reported in our sample may be related to the current sample having been in remission for leukemia only, whereas the POQOLS normative sample included a broader range of diagnoses and phases of treatment. The relatively small, although statistically significant, differences (elevations) in PSI scores (for fathers in particular) may reflect the stresses associated with parenting a child with cancer in remission. The child reports of lower levels of anxiety than norms is a consistent finding in the oncology literature, with low levels of both anxiety and depression generally reported.
Table I. Sample Means and Normative Data for All Measures

<table>
<thead>
<tr>
<th>Measure</th>
<th>Mothers</th>
<th>Fathers</th>
<th>Norms</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M</td>
<td>SD</td>
<td>M</td>
</tr>
<tr>
<td>PSI-Total Score</td>
<td>73.35</td>
<td>20.03</td>
<td>76.70</td>
</tr>
<tr>
<td>PSI-Parental distress</td>
<td>26.43</td>
<td>10.84</td>
<td>26.45</td>
</tr>
<tr>
<td>PSI-Parent-Child</td>
<td>18.44</td>
<td>5.58</td>
<td>20.91</td>
</tr>
<tr>
<td>PSI-Difficult child</td>
<td>28.07</td>
<td>9.16</td>
<td>29.95</td>
</tr>
<tr>
<td>POQOLS-Total</td>
<td>61.19</td>
<td>19.85</td>
<td>54.34</td>
</tr>
<tr>
<td>POQOLS-Restrict function</td>
<td>24.72</td>
<td>9.75</td>
<td>22.10</td>
</tr>
<tr>
<td>POQOLS-Emotion distress</td>
<td>22.22</td>
<td>7.59</td>
<td>18.18</td>
</tr>
<tr>
<td>POQOLS-Response Tx</td>
<td>14.98</td>
<td>6.54</td>
<td>13.93</td>
</tr>
<tr>
<td>Reaction index</td>
<td>24.09</td>
<td>13.71</td>
<td>19.86</td>
</tr>
<tr>
<td>STAI State Anxiety</td>
<td>34.30</td>
<td>13.06</td>
<td>35.09</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*PSI = Parenting Stress Index, POQOLS = Pediatric Oncology Quality of Life Scale. The sample child mean (46.29) and standard deviation (10.89) for the Revised Children's Manifest Anxiety Scale are significantly lower than normative values.

*Norms are from scale manuals with the exception of the Reaction Index for which no community norms are available. Rather than utilize traumatized groups, means and standard deviations are reported from comparison families with no medically ill children (Kazak, Barakat, et al., 1997).

The top value is for mothers and the lower for fathers.

*p < .01 (for t tests with normative data).

*p < .001 (for t tests with normative data).

moment correlations were conducted, separately examining associations between parenting stress and QOL for mothers and fathers while their child was treated for leukemia with mother, father, and child reports of adjustment after ending treatment.

The total score for parenting stress during treatment was strongly and significantly associated with state anxiety for mothers ($r = .55, p = .009$) and fathers ($r = .57, p = .015$) (Tables II and III). For fathers it was also associated with posttraumatic stress symptoms on the Reaction Index ($r = .58, p = .015$). For both mothers and fathers, the Parental Distress subscale of the PSI during treatment was most strongly correlated with the Reaction Index ($r_{mothers} = .47, p = .023, r_{fathers} = .69, p < .001$) and with state anxiety ($r_{mothers} = .55, p = .007, r_{fathers} = .64, p = .002$). For mothers, the Parent–Child Dysfunctional interaction subscale of the PSI also correlated significantly with state anxiety after treatment ended ($r = .54, p = .009$). There were no significant associations between the Difficult Child subscale of the PSI and later outcome, for either parent. Nor were any of the PSI scores associated with child anxiety off-treatment.

Total parent-reported child QOL scores during treatment were significantly associated with mothers' off-treatment posttraumatic stress symptoms ($r = .64, p = .002$) and state anxiety ($r = .43, p = .049$). Consistent relationships were seen
Predicting Adjustment

Table II. Mothers' Parenting Stress and Quality of Life During Treatment for Childhood Leukemia and Mothers' Posttraumatic Stress Symptoms and Mother and Child Anxiety After Treatment Ends

<table>
<thead>
<tr>
<th>Measure*</th>
<th>Reaction index</th>
<th>State anxiety</th>
<th>Child anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSI-Total</td>
<td>.39</td>
<td>.55*</td>
<td>.42</td>
</tr>
<tr>
<td>PSI-Parental distress</td>
<td>.47*</td>
<td>.55*</td>
<td>.21</td>
</tr>
<tr>
<td>PSI-Parent-child</td>
<td>.38</td>
<td>.54*</td>
<td>.30</td>
</tr>
<tr>
<td>PSI-Difficult child</td>
<td>.19</td>
<td>.38</td>
<td>.02</td>
</tr>
<tr>
<td>POQOLS-Total</td>
<td>.64*</td>
<td>.43*</td>
<td>.44</td>
</tr>
<tr>
<td>POQOLS-Restrict function</td>
<td>.37</td>
<td>.23</td>
<td>.03</td>
</tr>
<tr>
<td>POQOLS-Emotion distress</td>
<td>.51*</td>
<td>.48*</td>
<td>.64*</td>
</tr>
<tr>
<td>POQOLS-Response Tx</td>
<td>.37</td>
<td>.23</td>
<td>.03</td>
</tr>
</tbody>
</table>

*PSI = Parenting Stress Index, POQOLS = Pediatric Oncology Quality of Life Scale.
*p < .05.
*p < .01.
*p < .001.

between the emotional distress subscale of the POQOLS and maternal posttraumatic stress symptoms (r = .51, p = .017), state anxiety (r = .48, p = .025), and child anxiety (r = .64, p = .003). This subscale is the only measure significantly associated with the child anxiety measure and is the only association for fathers' QOL (r = .50, p = .035).

DISCUSSION

While it is generally believed that the level of adjustment of families at diagnosis and during treatment for childhood cancer is indicative of later adjust-

Table III. Fathers' Parenting Stress and Quality of Life During Treatment for Childhood Leukemia and Fathers' Posttraumatic Stress Symptoms and Father and Child Anxiety After Treatment Ends

<table>
<thead>
<tr>
<th>Measure*</th>
<th>Reaction index</th>
<th>State anxiety</th>
<th>Child anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>PSI-Total</td>
<td>.58*</td>
<td>.57*</td>
<td>.24</td>
</tr>
<tr>
<td>PSI-Parental distress</td>
<td>.69*</td>
<td>.64*</td>
<td>.37</td>
</tr>
<tr>
<td>PSI-Parent-child</td>
<td>.33</td>
<td>.38</td>
<td>.26</td>
</tr>
<tr>
<td>PSI-Difficult child</td>
<td>.27</td>
<td>.27</td>
<td>-.07</td>
</tr>
<tr>
<td>POQOLS-Total</td>
<td>-.06</td>
<td>.20</td>
<td>.20</td>
</tr>
<tr>
<td>POQOLS-Restrict function</td>
<td>-.11</td>
<td>.06</td>
<td>.05</td>
</tr>
<tr>
<td>POQOLS-Emotional distress</td>
<td>.25</td>
<td>.37</td>
<td>.50*</td>
</tr>
<tr>
<td>POQOLS-Response Tx</td>
<td>-.38</td>
<td>.06</td>
<td>-.11</td>
</tr>
</tbody>
</table>

*PSI = Parenting Stress Index, POQOLS = Pediatric Oncology Quality of Life Scale.
*p < .05.
*p < .01.
*p < .001.
ment, there are very few studies that provide prospective data to shed light on these important clinical observations. The relationships found in the present study between parenting stress and parent report of child quality of life during treatment for childhood leukemia and later parental posttraumatic stress symptoms and state anxiety are intriguing for the strong associations found.

Higher levels of parenting stress for both mothers and fathers during treatment were associated with higher state anxiety after their child completes treatment. For fathers, a significant association with posttraumatic stress and earlier parenting stress was also present. These data suggest that evaluations of parenting stress early in the illness course may help identify families who will continue to experience higher levels of anxiety, even after treatment ends. A closer look at the data is even more instructive, as the strongest associations are with the subscale of the PSI that specifically pertains to the distress of parents themselves. For mothers, parent-child interaction was significantly correlated with later outcome which may reflect the generally more focused role of mothers on caregiving during treatment. Interestingly, the Difficult Child scale of the PSI did not predict any outcomes. It may be that in pediatric treatment centers, the focus of parents and staff on children helps mitigate long-term consequences. In contrast, parents may receive less support and have fewer psychological resources provided for managing their own distress.

Parents’ perceptions of child quality of life were related to later parental adjustment for mothers, but less so for fathers. For mothers, overall evaluations of quality of life during treatment were predictive of later parental outcome. However, the strongest relationships were for the Emotional Distress scale of the POQOLS scale. These data indicate that parental perceptions of the child’s overall adjustment (incorporating both internalizing and externalizing) behaviors are more potent predictors of long-term family adjustment than the more immediate concerns of acute treatment, as assessed by the other two POQOLS subscales.

Children’s reports of their own anxiety after treatment ends was significantly associated with only the Emotional Distress scale of the POQOLS (both mother and father report) during treatment. While the present data set does not allow for direct comparisons of child report during treatment, the lack of other associations may reflect the generally low levels of concordance between parents and children, particularly for measures of internalizing behavior. It may also be that parents resolve many parenting concerns over the course of treatment and after treatment ends and that the direct effects on children are therefore not seen. There are also many potentially important moderating and mediating variables which could impact on these complex outcomes which are unfortunately beyond the scope of the present study to explore. The data speak, however, to the importance of attending to the emotional responses of parents and children during treatment and suggest that these are more salient predictors than more acute physical factors.
Cautious interpretation of these data is urged due to the small sample, the dangers inherent in overinterpreting simple correlations, and the limitations necessitated by the design. Using a true prospective design and a larger sample, the effect of respondent style could be addressed statistically. That is, as in any prospective study, some portion of the variance can be attributed to consistency in personality and response style over time. Conversely, while cross-informant data are important and would further strengthen research in this field, they too must be couched and interpreted with respect to differences in perspective by person.

However, the lack of prospective studies and the clinical relevance of our data argue for their viability and the importance of replication and expansion. The most well-established psychological interventions for children in pediatrics are individually (child) focused. The current data support the importance of implementing more contextual approaches and considering approaches that directly evaluate and intervene with parental (both mothers and fathers) and child distress. That is, a significant subset of parents continue to experience distressing symptoms of posttraumatic stress after treatment ends. We may be able to identify them early on in treatment and develop targeted, specific interventions to reduce distress over the course of serious childhood illness.

REFERENCES


