# Brief Report: Parents of Children Undergoing Bone Marrow Transplantation: Documenting Stress and Piloting a Psychological Intervention Program

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*Objective:* **To document levels of stress in parents of children undergoing bone marrow transplantation (BMT) over the course of hospitalization and to pilot a psychological intervention program designed to teach parents techniques for managing stress associated with their child's illness and hospitalization.**
*Methods:* **Twenty-two mothers of children (ages 2–16) undergoing BMT were followed prospectively from preadmission to three weeks posttransplant. Eleven mothers, randomly assigned to participate in a pilot intervention program, were compared with 11 control mothers receiving standard care preparation of their child's BMT.**
*Results:* **Repeated measures ANOVAs detected significant changes in stress over time, with most stress reported preadmission. Mothers in the intervention condition reported using more stress management techniques than mothers in the standard care condition, though the majority of analyses revealed no significant differences in stress between groups.**
*Conclusions:* **Increased levels of parenting distress may occur pretransplant, suggesting the need for additional psychological intervention at that time.**

*Key words:* *bone marrow transplant; parental adjustment; psychological intervention; stress.*

Through the course of their treatment, children undergoing bone marrow transplantation (BMT) experience stressful procedures typical of other children with cancer (e.g., chemotherapy, bone marrow aspirates, and lumbar punctures). However, BMT may be associated with additional stressors given the often lengthy hospitalization and associated restrictions upon discharge (e.g., limited contact with loved ones and friends). The available literature on the psychological impact of pediatric BMT suggests that these children may be stressed; exhibit poor adherence; have low social competence, self-esteem, and emotional well-being; and have multiple concerns upon discharge (McConville et al., 1990; Phipps et al., 1995; Wiley & House, 1988). In fact, Stuber, Nader, Yasuda, Pynoos, and Cohen (1991) found that five out of six children studied were in the moderate range of posttraumatic stress symptomatology 3 months following BMT.

Researchers have also considered symptoms of stress in BMT family members (Heiney, Neuberg,

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Myers, & Bergman, 1994). Findings reveal elevated levels of distress associated with the process of parental informed consent to BMT (Dermatis & Lesko, 1990), parenting (Rodrigue et al., 1996), and parents' fears of possible relapse (Sormanti, Dungan, & Rieker, 1994). As studies of parents' stress have largely been cross-sectional, little is known about how their stress changes as a function of their child's treatment.

A variety of psychological interventions have been designed in an effort to decrease the potentially negative psychological consequences for children with cancer. Most interventions have been designed specifically for children and typically include behavioral techniques such as distraction, guided imagery, or progressive muscle relaxation. Five studies have incorporated parents into interventions (Hoekstra-Weebers, Huevel, Jaspers, Kamps, & Klip, 1998; Jay & Elliott, 1990; Kazak et al., 1999; Kazak, Blackall, Himelstein, Brophy, & Daller, 1995; Kupst & Schulman, 1988), although none included children undergoing BMT. No reported intervention research has been conducted examining parent and family issues specific to pediatric BMT. Based on what is known about these families, as well as the reported benefit of interventions to assist with difficulties related to general childhood illness, we thought it worthwhile to examine parents' psychological response to their child's BMT throughout hospitalization and to design an intervention for families of children undergoing BMT.

This study had two main foci: (1) documenting stress over time in parents of children undergoing BMT, and (2) piloting a newly designed psychological intervention to better manage stress in parents of children undergoing BMT. We hypothesized that reported stress would be highest shortly after the child's admission, just prior to transplantation. We also hypothesized that subsequent to our treatment, parents in the intervention condition (IN) would report using more treatment techniques and similarly report lower levels of stress than those participants in the standard care condition (SC).

## Method

### Participants

Parents of children scheduled to undergo inpatient BMT at a large teaching hospital in the southeastern United States were invited to participate. During a 16-month period (8/96 to 11/97), a total of 24 parents were approached for study and 22 (92%) agreed to enroll. All volunteers were English-speaking mothers of children ages 2–16 self-identified as being the primary caretaker during hospitalization. All children were admitted to the same BMT unit, consisting of laminair air flow isolated rooms. Parents were not restricted in their visitation and frequently chose to spend the night in their child's room.

Demographic and illness characteristics of the sample are reported in Table I. Most mothers were married, Caucasian, and had achieved a high school education. The majority of children undergoing BMT were boys (M age = 8 years), with a cancerous (n = 19; Ewing's sarcoma, n = 5, neuroblastoma, n = 5, AML, n = 4, ALL, n = 3, osteosarcoma, n = 1, Hodgkin's lymphoma, n = 1), or noncancerous (n = 3) disorder for which BMT was selected as the

**Table I.** Background Data

| Variable | Intervention n (%) | Standard Care n (%) |
|---|---|---|
| Child characteristics | | |
| Age (years; $M \pm SD$) | 9.4 ± 4.5 | 8.0 ± 5.2 |
| Male | 8 (73) | 9 (82) |
| Female | 3 (27) | 2 (18) |
| Grade in school ($M \pm SD$) | 4.5 ± 3.5 | 3.5 ± 4.2 |
| Caucasian | 9 (82) | 9 (82) |
| African American or Hispanic | 2 (18) | 2 (18) |
| Illness characteristics | | |
| Cancerous? (yes) | 9 (82) | 10 (91) |
| Length of diagnosis[a] (months; $M \pm SD$) | 11.0 ± 5.7 | 10.8 ± 8.3 |
| Type of transplant | | |
| Allogeneic | 5 (45) | 3 (27) |
| Autologous | 2 (18) | 4 (36) |
| Cord blood | 1 (9) | 2 (18) |
| Stem cell | 3 (27) | 2 (18) |
| Previous hospitalizations[b] | 33.4 ± 35.2 | 18.2 ± 19.4 |
| Parent characteristics | | |
| Age (years; $M \pm SD$) | 37.2 ± 5.2 | 36.5 ± 8.5 |
| Education (years; $M \pm SD$) | 13.1 ± 3.1 | 12.9 ± 2.7 |
| Marital status | | |
| Married | 6 (55) | 7 (64) |
| Single/separated/divorced/ widowed | 5 (45) | 4 (36) |
| Number of hours from home to hospital | 3.1 ± 1.8 | 2.4 ± .83 |

[a]For cancerous disorders only, given that the children with noncancerous disorders were diagnosed shortly after birth.
[b]Number of hospitalizations ranged from 1–100; median number of hospitalizations was 12.

treatment of choice; no child studied had previously been treated by BMT.

### Procedure

Study procedures were approved by the university's health science center institutional review board. All participants received the Division of Hematology/Oncology's standard preparation procedure at the time of the child's comprehensive pretransplant evaluation (i.e., usually 2 to 4 weeks before BMT unit admission). Parents were assessed across six time points. The first assessment served as a baseline measure completed an average of 13 days (range 1–47 days) prior to the child's BMT unit admission. After baseline assessment, participants were randomly assigned to either the IN or SC condition. All subsequent measures were administered during hospitalization, by a research assistant blind to the participant's condition. At this institution, the BMT date was scheduled several weeks in advance, and the child's conditioning regimen usually began 7 days before transplant. The second assessment was completed 7 days prior to transplant (day $-7$), and the remaining assessments were conducted at weekly intervals through three weeks post-transplant (days 0, $+7$, $+14$, $+21$).

*Intervention.* IN participants were seen by an advanced clinical psychology graduate student for one 90-minute session in the hospital's psychology clinic. Intervention sessions were scheduled at the convenience of the family and were typically held within 1 week of the child's admission to the BMT unit (range 0–30 days prior to admission). The intervention followed a stress inoculation model found to be effective for a variety of stressful situations (Jay & Elliott, 1990). A parsimonious one-session treatment format was chosen to simplify scheduling, decrease family burden, and maximize external validity. Included in the intervention were three main components: education, relaxation, and communication. IN parents received handouts illustrating the components of the intervention through concrete examples, as well as a tape-player headset to increase their likelihood of practicing the relaxation training. (Detailed information about the intervention and semi-structured interview is available from Randi Streisand upon request.)

To assure the integrity of the intervention, treatment sessions were videotaped. Trained research assistants who were blind to the study's hypotheses examined a randomly selected subset of interven-

tions ($n = 5$) for content comparison to a detailed treatment outline. Results from rater 1 yielded 100% adherence to the intervention outline, and rater 2's scored treatment integrity was 97.8%.

### Measures

*Daily Stress Inventory (DSI).* The DSI is a 58-item self-report instrument assessing the impact of minor stressful events on a daily basis (Brantley, Waggoner, Jones, & Rappaport, 1987). The number of events endorsed as having occurred, and the sum of the impact ratings of those events, comprise the Events and Impact scores. We computed DSI scores for six time points: baseline through day $+21$. Adequate concurrent and construct validity, as well as good reliability, have been demonstrated (Brantley & Jones, 1993; Brantley et al., 1987). Coefficient alphas for the Event scale in our sample ranged from .94 to .98.

*Parenting Stress Index (PSI)* We administered the Parent Domain of the PSI, consisting of 53 self-report items that measure the relative magnitude of stress in the parent-child system (Loyd & Abidin, 1985), at baseline and at day $+21$. The Parent Domain indicates the degree to which stress is related to parental functioning across seven areas. Coefficient alphas for the Parent Domain for our sample were .71 and .81 at preadmission and day $+21$, respectively.

*Semi-structured Interview (SSINT).* A semi-structured interview developed for this study assessed the *frequency* (14 items; 4-point Likert scale) of psychological and physiological symptoms of stress and the degree to which such symptomatology affected participants' lives; we asked if symptoms were a *change* (yes/no) from previous functioning and/or considered to be a *problem* (yes/no). Interviewers cued participants to consider the previous week in giving their responses. Seven additional items (7-point Likert scale) asked parents how stressed they felt during *specific* times in their child's medical care (e.g., most recent mouth care treatment, most recent dressing change). Administration of the SSINT therefore yielded four scores: frequency, change, problem, and specific stress. Coefficient alphas for the *frequency* score ranged from .71 to .85. Participants responded to the SSINT at four time points (pretransplant, day $-7$, day $+14$, and day $+21$) throughout their child's BMT experience.

*Adherence.* Participants completed a checklist of the various intervention techniques used during the

previous week, at day −7, day 0, day +7, day +14, and day +21.

## Results

### *Analyses*

Planned analyses of variance (ANOVAs) were conducted on demographic information and self-report measures of stress to determine differences between groups at baseline. Repeated measures ANOVAs were computed for each measure of stress. Because of the small sample size and preliminary nature of our research questions, we did not correct for multiple comparison error and instead report ANOVAs and $t$ tests with a $p$ value of <.05 as significant. When appropriate, Welch's $t$ statistics (Nunnally & Bernstein, 1994) were calculated to compare data from this sample with published normative data.

### *Time Effects*

*DSI.* There was a main effect for time on both the impact, $F(5, 90) = 3.27$, $p < .02$ (see Figure 1), and event, $F(5, 85) = 4.5$, $p < .002$, scales of the DSI. In contrast to our hypothesis that stress would be maximized after admission and just prior to transplantation (day −7), post-hoc paired samples $t$ tests indicated that stress was higher preadmission for the DSI impact scale than compared to weeks one, two, and three posttransplant: day +7, $t$ (18) = 2.70; day +14, $t$ (18) = 2.65; day +21, $t$ (18) = 2.49; all $p$s <.05. Post-hoc comparisons of the event scale yielded similar findings, with more stress reported at baseline as compared to all other data points except for 3 weeks posttransplant: day −7, $t$ (20) = 2.58; day 0, $t$ (20) = 2.89; day +7, $t$ (18) = 3.20; day +14, $t$ (18) = 3.26; all $p$s <.05.

*PSI.* There was a significant main effect for time for two of the PSI subscales as well. Mothers reported significantly less stress related to their competence as parents and in terms of role restriction at 3 weeks posttransplant (day +21) compared to preadmission, $F(1, 17) = 10.9$, $p < .005$, $F(1, 17) = 4.72$, $p < .05$, respectively, further suggesting that preadmission was a particularly stressful time.

*SSINT.* For the semi-structured interview, the only significant finding was for specific stress, $F(3, 60) = 7.83$, $p < .002$. Follow-up comparisons indi-
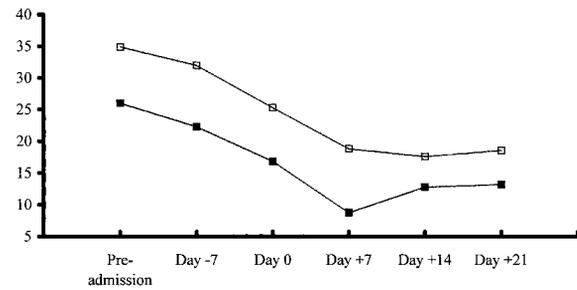


**Figure 1.** Daily Stress Inventory impact scale scores reported by standard care (SC) and intervention (IN) participants. Open square = SC participants; filled square = IN participants.

cated that stresses related to their child's medical care (e.g., waiting for test results, interacting with nurses, and dressing changes) were more pronounced preadmission for BMT than at 1 week posttransplant (day +7, $t$ [21] = 2.37, $p < .03$) or 3 weeks posttransplant (day +21, $t$ [10] = 3.69, $p < .009$). These results corroborate data obtained from both the DSI and PSI, indicating substantial parental stress preadmission.

### *Group Effects*

Table II presents means for both groups at day +21. In contrast to our hypotheses, there were no significant main effects for group on the self-report measures or any of the four scores of the SSINT. As expected, a significant group main effect for use of intervention techniques was found, with IN mothers reporting use of a greater number of intervention techniques than SC mothers, $F(1, 18) = 5.78$, $p < .03$.

### *Examination of Clinical Significance*

In order to examine the relative magnitude of stress of the parents in our study, we compared responses on standardized measures of stress to other relevant samples. On both the PSI and DSI, responses of parents in our sample were not in the clinically significant ranges. Participants' scores on the PSI were compared to a primarily nonclinic-referred normative sample (Abidin, 1995), a sample of 20 parents of preschool age children with diabetes (Wysocki, Huxtable, Linscheid, & Wayne, 1989), and 36 parents of children undergoing an evaluation for transplantation (both solid organ and BMT; Rodrigue et al., 1996). At both preadmission and day +21, mothers in our sample reported significantly less

**Table II.** Means and Standard Deviations for Measures of Stress at Preadmission and Day +21

| Measure | Intervention (IN) | | Standard care (SC) | |
|---|---|---|---|---|
| | Preadmission | Day +21[a] | Preadmission | Day +21[a] |
| Daily Stress Inventory[b] | | | | |
|   Impact | 26.0 ± 20.2 | 13.2 ± 9.6 | 34.9 ± 36.3 | 18.6 ± 15.9 |
|   Event | 11.1 ± 6.1 | **6.4 ± 4.1** | 12.8 ± 9.2 | **10.4 ± 7.2** |
|   *n* | 11 | 10 | 11 | 10 |
| Parenting Stress Index[b] | | | | |
|   Attachment | 11.1 ± 3.1 | 11.2 ± 3.9 | 13.3 ± 3.5 | 11.0 ± 2.3 |
|   Competence | 28.9 ± 7.4 | 30.1 ± 6.9 | 30.1 ± 6.9 | 26.9 ± 5.6 |
|   Depression | 16.4 ± 6.4 | 15.3 ± 5.2 | 19.7 ± 5.2 | 15.8 ± 4.7 |
|   Health | 10.6 ± 4.1 | **10.0 ± 3.4** | 12.2 ± 3.8 | **11.7 ± 3.0** |
|   Isolation | 11.8 ± 5.2 | **9.6 ± 2.6** | 13.8 ± 4.8 | **13.2 ± 4.1** |
|   Role restriction | 16.1 ± 5.4 | **13.1 ± 5.1** | 19.6 ± 7.4 | **16.3 ± 4.6** |
|   Spouse | 14.5 ± 6.7 | **15.7 ± 6.0** | 18.6 ± 6.1 | **19.7 ± 7.1** |
|   Parent Domain | 103.9 ± 27.4 | **100.1 ± 20.1** | 116.4 ± 27.6 | **114.6 ± 24.7** |
|   *n* | 10 | 10 | 11 | 10 |
| Semi-structured interview | | | | |
|   Frequency | 6.6 ± 6.1 | 5.8 ± 6.2 | 9.5 ± 6.8 | 5.8 ± 4.6 |
|   Specific stress | 16.5 ± 7.5 | 8.3 ± 2.7 | 12.0 ± 5.2 | 8.5 ± 3.7 |
|   *n* | 11 | 10 | 11 | 10 |

Higher scores indicate greater reported stress for all measures. Boldface values within the same measure of stress indicate medium to large effect sizes (> .50) between the IN and SC groups at day +21.
[a]One SC parent withdrew from the study and one IN parent's child died prior to the end of data collection. These parents' data were not included in analyses at end time points.
[b]Levels of stress are not clinically significant compared to normative samples.

stress, as indicated by the Parent Domain score, than both the normative sample and the sample of parents of children with diabetes (all $ps < .05$). Responses of parents in our sample were not statistically different from those for the sample of parents of children in the evaluation phase of transplantation.

Similar findings emerged when comparing parents' ratings on the DSI to a normative sample of medical patients ($N = 223$; Brantley & Jones, 1993). Parents' impact scores for days +7, +14, and +21 were significantly lower than the normative sample (all $ps < .05$). Participants did report a greater number of stressful events at baseline than the normative sample, yet impact ratings for the events did not differ significantly between samples.

## Discussion

This study is the first to prospectively measure stress in mothers of children undergoing BMT at regular intervals and to pilot a psychological intervention to assist parents in managing their stress. Results indicated three main findings: (1) increased stress preadmission, (2) parents' ability to learn and put into

practice techniques from the intervention, and (3) subclinical distress among parents compared to healthy norms.

The most robust findings were multiple effects over time, with mothers in both groups reporting significantly more stress preadmission than at any other time. Contrary to our hypothesis that stress would be greatest just prior to transplantation (day −7), stress decreased dramatically once the pretransplant conditioning phase began. We believed that stress would be amplified given that the conditioning phase depletes children's immune functioning, often signaling a "point of no return." Perhaps knowledge that the long-anticipated treatment had finally begun reduced stress for those parents who had assumed primary caregiving responsibility. These findings are consistent with results from previous BMT investigations, as well as those focusing on solid organ transplantation (Phipps et al., 1995; Rodrigue et al., 1996).

Our second finding, that IN mothers reported the use of significantly more intervention techniques than SC mothers, suggests that the pilot intervention was successful in teaching parents strategies to manage stress. As we did not have an objective measure of whether the parents actually

used the techniques, further validation of their effectiveness is needed.

The third main finding, that mothers' level of stress, in general, was not clinically different from that of normative samples, was surprising. There are at least two possible interpretations of this finding. First, the primary burden of care at the time of the child's BMT hospitalization shifts from mothers to the unit nurses and staff, which may provide a much needed respite and, perhaps paradoxically, stress reduction. Second, it is possible that the types of stressors encountered by mothers were not well detected by our outcome measures, or that floor effects affected our ability to detect such changes, highlighting the need for more specific assessment tools.

In regard to the pilot of our intervention, stress did not differ significantly between the intervention and standard care groups. Results may have been significant with a larger sample or more specific outcome measures. Other investigations with relatively small sample sizes of chronically ill children and their parents have also failed to yield statistically significant differences between intervention and control conditions for a variety of reasons (Hoekstra-Weebers et al., 1998; Kupst & Schulman, 1988; Robinson & Kobayashi, 1991). Methodological challenges in our and others' treatment outcome studies include randomization to standard care, relevance of nonpediatric assessment tools (La Greca & Lemanek, 1996), and lack of statistical power.

Even though parents' level of stress was not significantly different from that of normative samples, our finding of changes in stress over time still suggests that, as compared to the hospitalization portion of BMT, the preparation period can be intensive and stressful. For pediatric BMT, this finding further highlights the importance of pretransplant psychological assessments that occur a significant amount of time prior to the BMT admission, as well as the development, implementation, and evaluation of interventions aimed at assisting parents during the time of pretransplantation. Our pilot intervention did not specifically target handling preadmission stressors, such as beliefs about the upcoming transplant. In the future, we recommend that a modified intervention would be most beneficial to the extent that it (1) focuses on parents' preadmission stress (through use of cognitive-behavioral and family therapy techniques), (2) is administered several weeks preadmission, (3) continues in some capacity (e.g., weekly phone contact) throughout the preadmission process in order to encourage parents to utilize strategies, and (4) includes all possible caretakers (whenever possible), shifting the focus from maternal stress to that of the family. In addition to refining the intervention, designing situation-specific and psychometrically sound measures is an important next step. Continued documentation of parents' stress as it relates to pediatric BMT is also necessary to enhance our understanding of longer-term issues, such as adjustment to discharge, reintegration of the family and child into school and community settings, and survivorship.

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