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# Adjustment in Parents of Children Undergoing Stem Cell Transplantation

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A B S T R A C T

Pediatric stem cell transplantation (SCT) is a demanding procedure for children and parents. Interventions to promote positive adjustment of parents in this setting are needed. A total of 171 patient-parent dyads from 4 sites received 1 of 3 interventions to reduce SCT-related distress: a child intervention with massage and humor therapy, an identical child intervention plus a parent intervention with massage and relaxation/imagery, or standard care. Parents completed weekly self-report measures of distress and positive affect during the acute phase of treatment (weeks −1 through +6); and measures of depression, posttraumatic stress (PTSD), and benefit finding at baseline and week +24. No significant differences across treatment arms were observed on repeated measures of parental distress. There was a marginally significant effect of the child intervention on parental positive affect. Over time, parental distress decreased significantly and positive affect increased significantly in all groups. Similarly, there were no significant intervention effects on the global adjustment outcomes of depression, PTSD, and benefit finding. However, reports of depression and PTSD decreased significantly and reports of benefit finding increased significantly from baseline to week +24 for all groups. Across all study arms, parent adjustment improved over time, suggesting that parents demonstrate a transient period of moderately elevated distress at the time of their child's admission for transplantation, followed by rapid improved to normative levels of adjustment. Similar to results previously reported for their children, these parents appear resilient to the challenges of transplantation.



## INTRODUCTION

A diagnosis of childhood cancer presents a significant adjustment challenge for both children and their families [1-4]. Fortunately, advances in medical treatment, including stem cell transplantation (SCT), have contributed to the increased survival rate of children with cancer. However, this high-risk procedure can create significant physical and emotional demands for both children and their parents [5-8].

Given that parents of children undergoing SCT can experience increased distress, it is important to consider designing and implementing effective interventions to promote positive adjustment of these parents. Furthermore, it appears that the emotional functioning of parents of children undergoing SCT is closely related to the child's psychological well-being—not only during active treatment, but after completion of SCT [5]. Therefore, implementing effective parent interventions is beneficial in that the interventions may also indirectly promote positive psychosocial functioning in pediatric patients. It has been suggested that parent interventions are implemented before or at the time of admission for SCT, given findings that suggest this to be a particularly distressing period for parents [7]. To date, limited research has examined interventions for parents of children with cancer, and in particular, those who have children undergoing SCT. Existing findings suggest that interventions have not significantly affected parent functioning, but in general, parents report lower levels of distress over time [9,10].

Given the lack of research in this area and the less than optimal methodological rigor that has been utilized to implement interventions for parents of children with cancer [11], further implementation and evaluation of randomized, methodologically sound parent interventions are warranted. Ideally, such investigations should use repeated measures to gain a better understanding of parent adjustment over the course of transplantation [12,13]. Therefore, the primary objective of this investigation was to examine the effects of both parent- and child-targeted interventions implemented during transplantation hospitalization on parental adjustment, using a repeated measures design.

Grounded in positive psychology, the intervention was focused not only on reducing distress but also on increasing the experience of positive emotions during this potentially stressful event. Although the primary goal of the intervention was to decrease distress and improve well-being in children undergoing transplantation, we also targeted and assessed intervention effects on parental adjustment. The

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study included 3 arms: (1) a child-targeted intervention involving massage and humor therapy; (2) the child intervention plus a parent-targeted intervention involving massage and relaxation and/or imagery; and (3) standard care. We sought to determine if there are additional benefits on parent psychological functioning from a parent intervention above and beyond the intervention provided to their children. The effects of the intervention on child outcomes have been previously reported [14,15]. This report focuses on parental outcomes. We hypothesized that parents who receive this health-promotion intervention (in addition to their child's intervention) during the acute phase of their child's SCT will show decreased emotional distress and increased positive adjustment in comparison with parents in the child-targeted arm of the intervention or those receiving only standard care.

## METHOD

### *Participants*

Participants were recruited from 4 major pediatric transplantation centers: St. Jude Children's Research Hospital, The Hospital for Sick Children, Toronto, Children's Hospital of Philadelphia, and Nationwide Children's Hospital, Columbus. Patient eligibility criteria included the following: (1) undergoing stem cell or bone marrow transplantation (allogeneic or autologous); (2) expected hospital stay of $\geq$ 3 weeks; (3) between the ages of 6 and 18 years; and (4) able to speak and read English fluently. Parent eligibility included the following: (1) primarily responsible for caring for the child during his/her hospital stay; (2) available to participate throughout the duration of the child's hospitalization for transplantation; and (3) ability to speak and read English fluently. Of the 278 patient-parent dyads approached for participation in the study, 242 dyads were eligible for study enrollment. A total of 189 (78.1%) patient-parent dyads initially consented to participate in the investigation. A final total of 171 completed baseline measures, were randomized to 1 of the 3 study arms, and were admitted to the hospital for transplantation. A detailed Consort diagram has been previously reported [14]. Descriptive statistics for demographic and medical variables are presented in Table 1. In summary, no significant differences were found among intervention arms on any of the medical (ie, site, type of transplantation, diagnostic group), or demographic (ie, child age, child gender, child race/ethnicity, resident parent) variables. For the parental outcomes presented here, there was an evaluable sample of 167 at baseline with gradual attrition to 97 at week +24. A total of 25 patients died, 11 withdrew (3 withdrew immediately after being randomized to the standard care arm; the remaining 8 withdrew after a period of noncompliance indicating they were no longer interested or felt study procedures were too burdensome), 8 were taken off study for medical reasons (relapse, second transplantation), and 22 failed the week +24 assessment. Comparison of baseline scores between those who provided a week +24 observation and those who did not revealed no significant differences on any of the outcomes reported here.

### *Procedures*

Patient-parent dyads were recruited before admission for transplantation. After informed consent and/or assent was obtained, parents completed baseline paper-and-pencil questionnaires and were subsequently randomized (stratified by child age group, site, and type of transplantation) to 1 of the 3 study arms: (1) a child-targeted intervention; (2) a child + parent intervention; and (3) standard care. The intervention was implemented beginning at admission through week +3 of transplantation.

### *Intervention*

*Child-targeted intervention*

Patients in this treatment group were provided with psychoeducation about the benefits of both massage and humor therapy, including ways in

**Table 1**
Demographic and Medical Characteristics of Parents and Child Patients

| | Child-Targeted Intervention | Child + Parent Intervention | Standard Care | Total (Across All Study Arms) | *P* Value |
|---|---|---|---|---|---|
| Child age, yr (M = 12.8, SD = 3.9) | | | | | .79 NS |
| 6-12 | 46.6 | 48.2 | 52.6 | 49.1 | |
| >12 | 53.4 | 51.8 | 47.4 | 50.9 | |
| Male gender | 67.2 | 55.4 | 52.9 | 59.1 | .24 NS |
| Race/ethnicity | | | | | .61 NS |
| White | 70.7 | 72.3 | 70.2 | 70.7 | |
| Black | 16.5 | 14.3 | 12.3 | 14.6 | |
| Hispanic | 5.2 | 3.6 | 7.0 | 5.3 | |
| Asian | 3.4 | 7.1 | 1.8 | 4.1 | |
| Other/unknown | 5.1 | 1.8 | 8.8 | 5.3 | |
| Socioeconomic status | | | | | .78 NS |
| I | 17.2 | 17.9 | 14.0 | 16.4 | |
| II | 39.6 | 33.9 | 35.0 | 36.2 | |
| III | 20.7 | 25.0 | 14.0 | 19.8 | |
| IV & V | 15.5 | 12.5 | 22.8 | 16.9 | |
| Unknown | 6.9 | 10.7 | 14.0 | 10.5 | |
| Resident parent | | | | | .46 NS |
| Mother | 84.7 | 85.7 | 76.7 | 82.4 | |
| Father | 10.2 | 8.9 | 16.1 | 11.7 | |
| Other | 5.1 | 5.4 | 7.1 | 5.8 | |
| Site | | | | | .33 NS |
| St. Jude | 46.6 | 36.8 | 38.3 | 41.5 | |
| HSC-Toronto | 15.5 | 26.1 | 31.6 | 23.9 | |
| CHOP | 24.1 | 19.6 | 19.3 | 20.5 | |
| NCH-Columbus | 13.8 | 17.5 | 10.7 | 14.0 | |
| Type of Transplantation | | | | | .35 NS |
| Autologous | 10.3 | 21.4 | 24.1 | 18.1 | |
| Allogeneic- matched sibling | 27.6 | 26.8 | 22.8 | 25.7 | |
| Allogeneic-other | 62.1 | 51.8 | 52.6 | 56.1 | |
| Diagnostic group | | | | | .98 NS |
| ALL | 27.1 | 26.8 | 26.3 | 26.9 | |
| AML | 23.7 | 21.4 | 28.6 | 24.6 | |
| Other leukemia | 10.8 | 17.9 | 12.5 | 13.5 | |
| HD/NHL | 13.6 | 8.9 | 8.7 | 10.5 | |
| Solid tumor | 12.2 | 12.5 | 12.5 | 12.3 | |
| Nonmalignancy | 12.2 | 12.5 | 10.7 | 11.1 | |

ALL indicates acute lymphoblastic leukemia; AML, acute myelogenous leukemia; HD, Hodgkin disease; NHL, non-Hodgkin Lymphoma; HSC, Hospital for Sick Children; CHOP, Children's Hospital of Philadelphia; NCH, Nationwide Children's Hospital; M, mean.
Data presented are %.