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## Preliminary Efficacy of a Brief Family Intervention to Prevent Declining Quality of Life Secondary to Parental Bone Marrow Transplantation

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### Abstract

The primary purpose of this research was to develop and evaluate the efficacy and feasibility of a brief, cost-effective family focused intervention to promote adaptive coping and quality of life throughout a parent's bone marrow transplantation (BMT). Targeted outcomes were cohesion, decreased use of avoidance coping, open communication, and effective management of emotional distress. Participants included an intervention group of 31 families and 29 families in a control group who received usual care. Each Family included the BMT recipient, a partner-caregiver, and children 10-18. The intervention included two dyadic sessions for the BMT recipient and the partner-caregiver, one individual session for the caregiver, and two DVDs for children. Statistical analyses indicated the intervention had a positive impact on at least one aspect of the adaptation of each family member. Caregivers reported the most distress but benefitted least from the intervention, whereas recipients and children reported improvement in distress. Ratings of satisfaction/acceptability were high with 97% responding they would recommend the intervention

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Conflict of Interest

The authors have no conflict of interest to report.

to others. Plans for future research include increased intervention intensity for the caregiver, a larger more diverse sample, and implementation over an extended period post-BMT.

## Keywords

quality of life; coping; adaptation; stress; preventive intervention; BMT; cancer

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## Introduction

Bone Marrow Transplantation (BMT) holds hope for treatment of cancers previously considered incurable, however, it is an exceedingly challenging and intrusive therapy. (1) It is associated with high levels of uncertainty and morbidity, and each family member along with the recipient, lives with the threat of unmet expectations and potential loss. It results in a crisis characterized by life-changing circumstances that disrupt family structure and interaction in ways that threaten the stability and the quality of life (QOL) of each member. (2-4) Therefore, being that it is the family which provides the milieu for the recovery and well-being of the recipient, it is the focus of this intervention.

A comprehensive review of 22 studies provides empirical evidence that the impact of BMT on surviving recipients results in a major psychological/social transition requiring individuals to revise their perspective of the world, themselves, and their future. (5) On the other hand, there has been minimal research concerning the psychological and social impact on family members and the family environment. Following hospital discharge, the family caregiver becomes the primary and often sole provider of physical care and emotional support for their spouse/partner. This is a time when recipients are particularly fragile and dependent, and unable to resume previous roles, however, there are few studies examining the vulnerability of these individuals who are crucial to the recipient's survival. They may be at the highest risk for development of secondary psychosocial morbidity, that is higher than the recipient, and at the same time they are essential to maintaining QOL within the family. (6)

A longitudinal study concerning the adaptation of 192 caregivers/partners of BMT recipients pre-hospitalization through one month following discharge, found although emotional distress declined it remained equivalent to the mean for psychiatric patients. (7) In an additional study based on qualitative interviews with 15 of these caregivers following discharge, they spoke of experiencing a lack of support and “having to go it alone”. (8)

Assessment of the impact of BMT on both recipients' and caregiver partners' satisfaction with their relationship over a one-year trajectory, found *increasing disparity* between them with caregivers reporting lower levels of satisfaction and higher levels of depression and anxiety. (6) Likewise, a study of family interaction found caregivers' level of satisfaction with this dyadic relationship to be consistently lower than that of recipients as measured prior to hospitalization through one year following treatment. However, based on a “coping with partner” sub-scale, dyads who engaged each other in managing the stress of BMT scored more positively on the total Dyadic Adjustment Scale, pointing to the importance of enhancing mutual support within this relationship. (9)

Distress experienced by children as a consequence of parental BMT has been minimally reported, however, many BMT recipients are young and have dependent children who must also adapt to the disruption. One study of 61 children between 10 and 18 years of age over a 12 month trajectory indicated the pre-hospitalization, pre-transplant period during family preparation was the most distressing. (10) Data obtained by interview directly from children indicated negative self-esteem, disruption in the roles particular family members traditionally assume, use of disengagement coping by the child, and the mother as transplant recipient were most strongly associated with negative adaptation.

Given these findings pointing to the negative impact of BMT on each family member, and the lack of interventions focusing on the family, the *primary aim* was to fill this gap and develop, refine, and determine the feasibility of delivering a brief, effective intervention to minimize secondary psychosocial morbidity. Specifically, the intervention was designed to reduce the level of emotional distress, to facilitate supportive functioning within the family, and to promote adaptive coping, thereby positively impacting QOL.

## Methods

### Research Design and Participant Families

This study included an intervention group and a control group of families receiving treatment as usual for BMT who had participated in exploratory research examining the issues they confront. Those findings then provided the basis for development of the intervention. (7-10) The recruitment procedure, points of data collection in the BMT trajectory, and measures were the same for both groups which were then matched for the analyses on BMT type - allogeneic or autologous, gender of the recipient parent, and the presence of at least one child participant 10-18 living in the home.

The intervention group included 31 families meeting the following criteria: (1) a parent undergoing an allogeneic or autologous BMT for the first time for the treatment of cancer; (2) a designated spouse/partner family caregiver in a committed relationship for a minimum of one year prior to BMT; (3) at least one child 10 - 18 living in the home willing to participate; (4) family members able to read and write English who had no issues that would interfere with their participation.

Families for both groups were recruited in collaboration with the BMT team at an NCI-designated cancer center using the same procedures. Approximately 72% of eligible families consented to participate in the exploratory study while approximately 78% consented to participate in the intervention study. Three families were recruited from a local community type hospital for the intervention group, and they received the same intervention by the study team. There were no statistical differences in the means of outcome variables in this group, and the feasibility of the intervention in these two types of healthcare settings was supported. Data were collected at the same time points in the BMT trajectory from the participants in both groups using the procedures and measures described below.

Data were collected from parents at three time points by self-report questionnaires that took approximately 40-45 minutes to complete: T1 - baseline prior to hospitalization and pre-

intervention; T2 - one month following discharge and completion of the intervention; T3 - four months following discharge. Data were collected from child participants by telephone interviews. A single co-investigator conducted all child interviews for both groups at the same time points in the trajectory that data were obtained from the parents. The interviews were approximately 40 minutes.

Individual participants were compensated as follows: parents, \$70 for the initial dyadic session, and \$40 for each questionnaire; children, \$25 for each data collection interview. Similar compensation for data completion was given to control participants. All procedures for both studies were approved by the Scientific Review Committee of the Indiana University Simon Cancer Center and the Institutional Review Board of Indiana University.

## Measures

### Demographics

Included were age, gender, race, education, marital status of the recipient and caregiver dyad, and type of transplant. See Table 1. A comparison of child participants in the two groups indicate they were highly similar. There were a greater number of males in both groups, the mean age for females in both groups and males in the control group was 16 years, with the mean for males in the control group being 15 years. All child participants were 10 - 18 and lived with the recipient.

### Measures of Variables in Figure 1

Figure 1 incorporates variables measured to indicate the responses of individual family members to the stress of BMT. It is based on the fundamental premise of system's theory that the response of each individual affects the responses of each other individual as well as interaction within the system. (17)

Participants in both the intervention and control groups completed the measures for each variable at the same time points in the trajectory, that is at each time point described above. The measures are described in Table 2.

### Intervention Components and Procedures

This manualized intervention was designed to maximize consistency and replicability, optimize the efficiency of delivery, and minimize costs. It is brief and based on the premise that the response of each family member has an impact on each other member, as well as on interaction within the family unit; (17, 18) therefore, all family members including the BMT recipient, the caregiver, and children 10 through 18 years of age were included as active participants. The intervention included two sessions for the parental dyad, one individual session for the caregiver, and two DVDs for children. An initial joint session with the recipient and caregiver partner was conducted in person or by telephone in preparation for hospitalization prior to admission, but following the collection of baseline data. Aims were to minimize dysfunctional family coping, reduce avoidance, promote open communication, and prepare for change and disruption in family living. The first DVD was also given prior to admission for transplant, one for autologous and one for allogeneic transplant. Content

included information about BMT, what to expect when visiting the hospital, and the importance of sharing concerns within the family.

Given the severe distress experienced by family caregivers, session two was held in person during hospitalization with the caregiver parent alone. The focus was promotion of self-care, stress management, handling concerns of children, and potential issues following discharge of the recipient. At this time, a second DVD was provided for children focusing on expectations and potential issues following hospitalization, and needs of the recipient that require adjustment of all family members. Participants kept the DVDs, they were encouraged to go back to them to get questions answered, and we strongly encouraged parents to view each of the DVDs with their children at least once.

The third intervention session was conducted by telephone two to three weeks following discharge with the caregiver/recipient dyad. It included discussion of concerns that came up following discharge, review of coping strategies being used by the dyad, and outside referrals for continued support that were made when necessary. Consistency and quality of the sessions were evaluated by audio recording with the written consent of participants, and they were then randomly evaluated throughout the intervention.

## Data Analysis and Results

### Qualitative Analysis: Acceptance and Feasibility

We evaluated acceptance and feasibility of the intervention along with preliminary efficacy by the T2 questionnaire following discharge for both caregivers and recipients. There were no differences in acceptability between them and their data were aggregated. Ninety-two percent agreed or strongly agreed the intervention helped meet the needs of their family. Specifically, 76% of participants agreed or strongly agreed the intervention facilitated coping effectiveness, 79% that it strengthened communication and support within the family, 74% that it increased feelings of personal control in managing daily life, and 84% agreed or strongly agreed the intervention enabled them to plan for change and help their children cope with stress. Regarding the intervention format, 92% responded the number and timing of sessions was adequate and appropriate, 90% agreed they were able to use the information, and 97% would recommend the intervention to others. Satisfaction among the children was gauged by consistency of participation. The only child participants in the intervention group who dropped out were those whose families dropped out primarily due to the decline and/or death of the recipient.

### Statistical Analysis

Demographic differences between the intervention and control groups were analyzed using the independent two samples t-test for continuous variables and a Chi-square test (Fisher's exact test) for categorical variables (Table 1). Statistics were conducted to examine the baseline data for significant differences (Table 3). There were no significant differences other than BMT type and we matched for that as explained below. Furthermore, due to the need to restrict the number of variables in the analysis only data from the oldest child in each family were included.

For all outcomes, if an item was missing an imputed mean was assumed for that item based on the mean of available items for an individual when at least 50% of the items for that outcome were not missing. The sample size available from each group for the analyses at each data point is given in Table 4.

Twenty-nine families were enrolled in the control group and 31 in the intervention group. There were no families in the control group that could be matched with those in the intervention group based on the gender of the BMT recipient and type of transplant, that is, female autologous recipients. Therefore, to maximize the sample size and balance the two groups, families were stratified into three subgroups: male/allogeneic BMT, male/autologous BMT, and female/allogeneic BMT. (19) Within each subgroup and within each family member, recipient, caregiver, and child, outcomes were analyzed using a linear mixed model for repeated measures that included group, time, and their interaction. Estimated means at each time point were obtained. Overall estimated means and standard errors were calculated by weighting across three subgroups according to their respective sample sizes. Consequently, within-group and between-group Cohen's *d* effect sizes were derived. Thresholds for interpretation of Cohen's *d* included effect sizes labeled as large ( $d \geq 0.80$ ), medium ( $0.50 \leq d < 0.79$ ), and small ( $0.20 \leq d < 0.49$ ). (20) Data were analyzed using SAS 9.4.

## Results

To summarize sample characteristics, there were more men than women recipients, more Caucasians, and most dyads were married. Ninety-eight percent attended high school or greater. The primary difference between groups was more recipients in the intervention group received an allogeneic BMT, generally associated with greater challenges.

Within-group and between group results on each outcome for both the intervention and control groups are shown in Table 5. Growth in cohesion was significantly marked with small effect sizes for the intervention group. Four months from baseline both recipients ( $d=0.43$ ) and caregivers ( $d=0.23$ ) experienced an increased sense of cohesion. Decreased emotional distress was evident for recipients in the intervention group at one month ( $d=0.30$ ) and four months ( $d=0.47$ ), and for control group recipients at four months ( $d=0.27$ ). Both intervention ( $d= 0.27$ ) and control ( $d= 0.34$ ) group caregivers experienced decreased distress at one month. Children in both groups also experienced decreased distress at one month ( $d=0.24$  for the intervention group, and  $d= 0.27$  for controls). A decrease in the use of avoidance coping was significantly marked with small effect sizes with less avoidance coping by recipients in the intervention group at one month ( $d=0.33$ ), and children in the intervention group at one month ( $d=0.34$ ) and four months ( $d=0.35$ ). An increase in expressiveness was displayed both by caregivers ( $d=0.20$ ) and children ( $d=0.28$ ) in the intervention group at four months.

Summarizing, between-group results at one and four months based on Table 5, for recipients small effect sizes were seen favoring the intervention group for cohesion at four months ( $d=0.38$ ), emotional distress at one month ( $d=-0.21$ ) and four months ( $d=0.22$ ), and avoidance coping at one month ( $d=0.40$ ). Among caregivers, small effect sizes favored the

intervention group for cohesion ( $d=0.24$ ) and expressiveness ( $d=0.24$ ) at four months while the effect size for emotional distress favored the control group ( $d=0.25$ ) at four months. Among children, small effect sizes favoring the intervention group were seen for avoidance coping at one month ( $d=0.27$ ) and expressiveness at four months ( $d=0.28$ ), while a small effect size favoring the control group was seen for cohesion at four months ( $d=0.21$ ).

## Discussion

The feasibility and preliminary effectiveness of this innovative family intervention in promoting stress management and a positive QOL for the BMT population was supported. The intervention was based on exploratory research designed to identify and understand the specific issues this population confronts when a family member undergoes BMT. (7-10) It is brief and covers the treatment trajectory prior to hospitalization through four months post-discharge, which is a particularly stressful and critical period. Furthermore, it has been developed to be translatable to the clinical setting.

There is growing interest in the role QOL may play in the successful outcome of BMT. (21) Particularly relevant to QOL was the finding of this study that although recipients spent much of their time in the hospital during the study trajectory, and therefore received less direct intervention than other family members, recipients in the intervention group were the only participants to experience less emotional distress --- possibly feeling the intervention would assist their families in navigating the stress resulting from their illness and treatment. They also expressed an increased sense of family cohesiveness as did the caregivers.

There was considerable concern on the part of professionals about including children in the study, however, no parents reported that their children became unduly upset and they readily participated in the data collection interviews sometimes sharing more than we requested. Talking with them by phone may have also increased their comfort level. In addition, Parents indicated in their evaluations that the intervention facilitated knowing how to help their children.

Open communication within the family and limiting the use of avoidance coping were emphasized. BMT recipients in the intervention group used less avoidance coping than those in the control group, and this was also true for children receiving the intervention. Notably, these children decreased the frequency with which they used this strategy across the trajectory. This is particularly important as research findings have shown family members tend to withdraw from each other in crisis situations for fear of increasing others' distress. (22)

The results of this trial indicate caregivers were not only the most highly distressed, they also benefitted least from the intervention despite an individual session during hospitalization. Therefore, future development needs to increase the intervention intensity for caregivers, as they are central to maintaining family stability and facilitating the recovery of the recipient. Exploratory analyses indicated when these dyads provided each other with mutual support they both were less distressed (9); therefore, interventions to facilitate

mutual support within the caregiver/recipient dyad could promote more positive adaptation for the caregiver in particular.

## Conclusions

The sample size of this feasibility study was limited, consequently the effect sizes were also modest; however, the intervention had a positive impact on one or more dimensions of the adaptation of each family member as indicated by statistical findings. Particularly important were indications of acceptance and participant satisfaction with 97% of caregivers and recipients responding they would recommend the intervention to others. Furthermore, it is translatable and can also be conducted by health professionals who are readily available in the clinical setting. No studies of family focused interventions incorporating both parents and children coping with the crisis of a life-threatening illness of a family member have been reported to date, yet, our exploratory research indicates no family member is left untouched, and each stands to benefit from the intervention.

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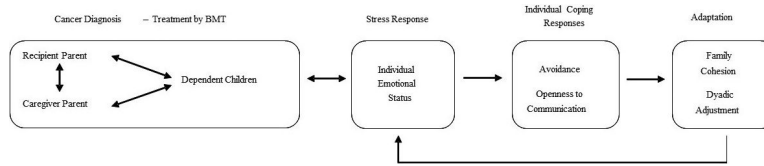
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## References

1. Gooley TA, Chien JW, Pergam SA, Hingorani S, Sorrow ML, Boeckh M, et al. Reduced mortality after allogeneic hematopoietic-cell transplantation. *N Engl J Med.* 2010; 363(22):2091–101. [PubMed: 21105791]
2. Fife, B., Fausel, C. Hematopoietic dyscrasias and stem cell/bone marrow transplantation. 2nd ed.. Oxford University Press; Oxford: 2010.
3. Keogh F, O'Riordan J, McNamara C, Duggan C, McCann SR. Psychosocial adaptation of patients and families following bone marrow transplantation: a prospective, longitudinal study. *Bone Marrow Transplant.* 1998; 22(9):905–11. [PubMed: 9827820]
4. Bishop MM, Beaumont JL, Hahn EA, Cella D, Andrykowski MA, Brady MJ, et al. Late effects of cancer and hematopoietic stem-cell transplantation on spouses or partners compared with survivors and survivor-matched controls. *J Clin Oncol.* 2007; 25(11):1403–11. [PubMed: 17416860]
5. Mosher CE, Redd WH, Rini CM, Burkhalter JE, DuHamel KN. Physical, psychological, and social sequelae following hematopoietic stem cell transplantation: a review of the literature. *Psycho-oncology.* 2009; 18(2):113–27. [PubMed: 18677717]
6. Langer S, Abrams J, Syrjala K. Caregiver and patient marital satisfaction and affect following hematopoietic stem cell transplantation: a prospective, longitudinal investigation. *Psychooncology.* 2003; 12(3):239–53. [PubMed: 12673808]
7. Fife BL, Monahan PO, Abonour R, Wood LL, Stump TE. Adaptation of family caregivers during the acute phase of adult BMT. *Bone Marrow Transplant.* 2009; 43(12):959–66. [PubMed: 19104493]



8. Von Ah D, Spath M, Nielsen A, Fife B. The Caregiver's Role Across the Bone Marrow Transplantation Trajectory. *Cancer Nurs.* 2015
9. Fife BL, Weaver MT, Cook WL, Stump TT. Partner interdependence and coping with life-threatening illness: the impact on dyadic adjustment. *J Fam Psychol.* 2013; 27(5):702–11. [PubMed: 23957849]
10. Spath ML, Fife BL, Monahan PO, Decker CL, Austin JK, Abonour R, et al. Children's emotional adaptation to parental BMT. *Bone Marrow Transplant.* 2013; 48(1):135–40. [PubMed: 22635242]
11. Watson D, Clark L. Manual for the Positive and Negative Affect Schedule - Expanded from the PANAS-X. 1994
12. Landgraf, J., Abetz, L., Ware, J. Child health Questionnaire (CHQ): A Users Manual. The Health Institute, New England Medical Center; Boston, MA: 1996.
13. Lazarus, R., Folkman, S. Stress, Appraisal, and Coping. Springer Publishing Company; New York: 1984.
14. Connor-Smith JK, Compas BE, Wadsworth ME, Thomsen AH, Saltzman H. Responses to stress in adolescence: measurement of coping and involuntary stress responses. *J Consult Clin Psychol.* 2000; 68(6):976–92. [PubMed: 11142550]
15. Moos, R., Moos, B. Family Environment Scale (FES). CPP/Consulting Psychologists Press; Palo Alto, CA: 1981.
16. Spanier G. Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *J Marriage Fam.* 1976; 38:15–28.
17. Cox MJ, Paley B. Families as systems. *Annual review of psychology.* 1997; 48:243–67.
18. Cowan, P., Hetherington, E. Family Transitions. Erlbaum; Hillsdale, NJ: 1991.
19. Rosenbaum P, Rubin D. Reducing Bias in Observational Studies using Subclassification on the Propensity Score. *J Am Stat Assoc.* 1984; 79(387):516–24.
20. Cohen, J. Statistical Power Analysis for the Behavioral Sciences: Edition 2. Routledge; 2013.
21. Hamilton BK, Law AD, Rybicki L, Abounader D, Dabney J, Dean R, et al. Prognostic significance of pre-transplant quality of life in allogeneic hematopoietic cell transplantation recipients. *Bone Marrow Transplant.* 2015; 50(9):1235–40. [PubMed: 26030045]
22. Harris J, Bowen DJ, Badr H, Hannon P, Hay J, Regan Sterba K. Family communication during the cancer experience. *J Health Commun.* 2009; 14(Suppl 1):76–84. [PubMed: 19449271]



**Figure 1.**  
A Theoretical Model of Adaptation to BMT within the Family Context

**Table 1**  
Demographic Characteristics of the BMT Recipient and Caregiver by Treatment Group at Baseline

Characteristics	BMT Recipient			Caregiver		
	Intervention (n = 31) <sup>a</sup>	Control (n = 29) <sup>a</sup>	P value <sup>b</sup>	Intervention (n = 31) <sup>a</sup>	Control (n = 29) <sup>a</sup>	P value <sup>b</sup>
<b>Age (year), mean (SD)</b>	45.53 (6.45)	46.74 (6.78)	0.486	43.91 (6.83)	44.64 (5.96)	0.661
<b>Gender</b>						
Female	12 (38.71)	8 (27.5)	0.361	19 (61.29)	20 (68.97)	0.533
Male	19 (61.29)	21 (72.41)		12 (38.71)	9 (31.03)	
<b>Race</b>						
Caucasian	27 (87.10)	25 (86.21)	0.430	28 (90.32)	27 (93.10)	>0.999
Non-Caucasian	0	2 (6.90)		2 (6.45)	2 (6.90)	
More than 1 Race	4 (12.90)	2 (6.90)		1 (3.23)	0	
<b>Marital status</b>						
Married	29 (90.32)	29 (100.00)	0.238	28 (90.32)	29 (100.00)	0.238
Living with Partner	3 (9.68)	0		3 (9.68)	0	
<b>Highest Education</b>						
Grade 8 or less	1 (3.23)	0	0.596	0	0	0.242
High School	9 (29.03)	4 (14.29)		11 (35.48)	8 (27.59)	
Vocational/Technical School	5 (16.13)	6 (21.43)		2 (6.45)	2 (6.90)	
Some College	7 (22.58)	8 (28.57)		10 (32.26)	4 (13.79)	
Four Year College Degree	8 (25.81)	7 (25.00)		7 (22.58)	11 (37.93)	
Graduate Degree	1 (3.23)	3 (10.71)		1 (3.23)	4 (13.79)	
<b>Type of BMT</b>						
Autologous	6 (19.35)	11 (37.93)	0.0007	NA	NA	NA
Allogeneic	25 (80.65)	18 (62.07)		NA	NA	NA

Abbreviations: BMT, bone marrow transplantation. NA, not applicable.

<sup>a</sup>Data are expressed as No. (%).

<sup>b</sup>Significantly different at  $P < 0.05$ .

**Table 2**

Table of Measures

Variable	Measure	Description of Measure	BMT recipient	Partner	Children	Cronbach's Alpha
<b>Contextual Factors</b>						
Socio-demographics and Illness Factors	Demographic Questionnaire	Items included socio-demographic information (family participants' ages, gender, race, education), marital status of the patient and caregiver, family annual income, and the patient's illness information (diagnosis, type of transplant). Data obtained at Time 1 from BMT recipient and/or partner.	X	X		
<b>Stress Response</b>						
Emotional Status	The Positive and Negative Affect Schedule (PANAS): Negative Affect Subscale Watson, Clark, & Tellegen, 1988 (Ref.11)  The Child Health Questionnaire (CHQ-CF87): Mental Health Subscale Landgraf, Abez, & Ware, 1996 (Ref. 12)	10 items - Negative affect as an indicator of parent distress. Participants rate how often they have experienced specific negative emotions (upset, sadness, scared, nervous) over the past two weeks prior to data collection. Ranked on a 5-point Likert scale with item responses ranging from "very slightly/not at all" to "extremely".  16 items pertaining to feelings: happy, sad, scared, lonely over the previous two weeks prior to data collection. Participants rated the frequency of these on a 5-point scale, with item responses ranging from "none of the time" to "all of the time".	X	X	X	.88  .82
<b>Individual Coping</b>						
Avoidance Coping	Ways of Coping Checklist Avoidance Subscale Lazarus & Folkman, 1984 (Ref.13)  Response to Stress Questionnaire (RSQ): Disengagement Subscale Connor-Smith, J., Compas, B. Wadsworth, M., Thomson, A. & Salzman, H. 2000 (Ref.14)	8 item subscale assessing the use of avoidance coping from a modified version of the Ways of Coping Checklist. Items included the frequency of the use of avoiding others, wishful thinking, distraction. Responses were ranked on a 5-point scale by the participant to indicate the frequency of use ("never" to "very often") of each behavior over the previous two weeks.  Nine item subscale asking children to rank the frequency of their use of disengagement coping behaviors (denial, avoidance, wishful thinking) with regard to their own previously identified stress-related aspects of their parent's BMT. Children rated their use on a 4-point scale, ranging from "not at all" to "a lot".	X	X	X	.83  .73
Communication	Family Environment Scale (FES): Expressiveness Subscale Moos & Moos, 2002 (Ref. 15)	9 items pertaining to the participants' perceptions of this construct for the two week time period prior to data collection. Items included: expressing feelings and concerns to one another, family discussion, and disclosure. Statements scored as "True" or "False".	X	X	X	.69 adults .45 children

Variable	Measure	Description of Measure	BMT recipient	Partner	Children	Cronbach's Alpha
<b>Adaptation</b>						
Family Cohesion	Family Environment Scale (FES) Subscale: Cohesion Moos & Moos, 2002 (Ref.15)	9 items pertaining to the participants' perceptions of this construct in the family for the two week time period prior to data collection. Items included: togetherness, spirit, getting along, and mutual support. Statements scored as "True" or "False".	X	X	X	.78 adults .75 children
Dyadic Adjustment	The Dyadic Adjustment Scale (DAS) Spanier, 1976 (ref.16)	32 item scale measures four relational elements: satisfaction, cohesion, consensus, and affectional expression in a marital/committed relationship of the recipient and caregiver/partner. The total score was used.	X	X		.90

Table 3

## Primary Outcomes with Group Equivalence at Baseline

Outcomes	BMT Recipient			Caregiver			Child		
	Intervention (n = 31) <sup>a</sup>	Control (n = 29) <sup>a</sup>	P value <sup>b</sup>	Intervention (n = 31) <sup>a</sup>	Control (n = 29) <sup>a</sup>	P value <sup>b</sup>	Intervention (n = 31) <sup>a</sup>	Control (n = 27) <sup>a</sup>	P value <sup>b</sup>
<b>Emotional Distress</b>	20.76 (7.29)	22.18 (8.20)	0.492	24.19 (9.11)	25.50 (7.49)	0.552	60.10 (10.08)	58.41 (8.94)	0.507
<b>Avoidance Coping</b>	13.77 (5.34)	13.28 (4.70)	0.715	13.44 (5.22)	15.42 (4.56)	0.127	19.38 (5.21)	17.81 (5.51)	0.282
<b>Expressiveness</b>	6.17 (1.84)	5.88 (1.91)	0.568	5.51 (1.91)	5.96 (2.20)	0.406	4.73 (1.82)	4.47 (1.92)	0.594
<b>Dyadic Adjustment Scale</b>	116.30 (15.66)	118.60 (17.00)	0.589	114.50 (16.88)	114.30 (20.28)	0.961	NA	NA	NA

Abbreviations: BMT, bone marrow transplantation.

<sup>a</sup>Data are expressed as Mean (SD).<sup>b</sup>Significantly different at  $P < 0.05$ .

**Table 4**

Sample Sizes for BMT Recipients and Caregivers at Each Data Point for Both Groups

Family Member	Visit	Control (N=)	Intervention (N=)
Caregiver	Baseline	29	31
	1-Month Post	26	19
	4-Months Post	24	16
Child	Baseline	27	31
	1-Month Post	25	22
	4-Months Post	23	16
Recipient	Baseline	29	31
	1-Month Post	25	19
	4-Months Post	24	15

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**Table 5**

Within-group and Between-group Effect Sizes of Outcomes

Outcome [Measures]	Within-Group Effects				Between-Group Effects	
	Intervention (n=31)		Control (n=29)		d (95% CI)	d (95% CI)
	Mean <sup>a</sup> (95% CI)	d (95% CI)	Mean <sup>a</sup> (95% CI)	d (95% CI)		
<b>Cohesion</b>						
<i>Recipient</i>						
Baseline	7.27 (6.00, 8.53)		7.01 (5.77, 8.24)			
1-Month Post	6.96 (5.33, 8.58)	-0.09 (-0.22, 0.05)	7.14 (5.79, 8.49)	0.04 (-0.07, 0.15)		-0.13 (-0.27, 0.01)
4-Months Post	8.83 (7.61, 10.04)	0.43 (0.26, 0.61)*	7.22 (6.16, 8.28)	0.06 (-0.05, 0.18)		0.38 (0.20, 0.57)*
<i>Caregiver</i>						
Baseline	6.71 (5.32, 8.10)		6.66 (5.25, 8.06)			
1-Month Post	6.63 (4.78, 8.48)	-0.02 (-0.15, 0.11)	6.67 (5.05, 8.30)	0.005 (-0.11, 0.11)		-0.03 (-0.17, 0.11)
4-Months Post	7.60 (6.13, 9.08)	0.23 (0.07, 0.38)*	6.63 (5.12, 8.13)	-0.01 (-0.13, 0.11)		0.24 (0.07, 0.40)*
<b>Child</b>						
Baseline	7.46 (6.40, 8.52)		6.92 (5.71, 8.13)			
1-Month Post	7.59 (6.20, 8.99)	0.04 (-0.08, 0.16)	6.78 (5.41, 8.14)	-0.04 (-0.15, 0.07)		0.09 (-0.04, 0.21)
4-Months Post	7.66 (6.58, 8.74)	0.07 (-0.10, 0.23)	7.79 (6.69, 8.89)	0.26 (0.14, 0.38)*		-0.21 (-0.39, -0.04)*
<b>Dyadic Adjustment Scale</b>						
<i>Recipient</i>						
Baseline	116.44 (106.82, 126.05)		117.87 (107.86, 127.88)			
1-Month Post	117.57 (108.31, 126.83)	0.04 (-0.09, 0.18)	119.61 (111.07, 128.16)	0.06 (-0.05, 0.17)		-0.02 (-0.16, 0.12)
4-Months Post	115.14 (103.79, 126.50)	-0.05 (-0.22, 0.13)	115.79 (103.45, 128.14)	-0.08 (-0.19, 0.04)		0.03 (-0.15, 0.21)
<i>Caregiver</i>						
Baseline	114.50 (104.88, 124.12)		114.05 (102.85, 125.24)			
1-Month Post	113.29 (102.28, 124.31)	-0.04 (-0.18, 0.09)	112.76 (101.13, 124.38)	-0.04 (-0.15, 0.06)		0.003 (-0.14, 0.14)
4-Months Post	113.54 (102.64, 124.44)	-0.04 (-0.19, 0.12)	111.03 (98.93, 123.13)	-0.10 (-0.22, 0.02)		0.07 (-0.09, 0.23)
<b>Emotional Distress</b>						



Outcome [Measures]	Within-Group Effects						Between-Group Effects	
	Intervention (n=31)			Control (n=29)				
	Mean <sup>a</sup> (95% CI)	d (95% CI)		Mean <sup>a</sup> (95% CI)	d (95% CI)	d (95% CI)		
<i>Recipient</i>								
Baseline	20.86 (16.14, 25.58)			22.23 (17.65, 26.81)				
1- Month Post	16.83 (12.22, 21.45)	0.30 (0.16, 0.44)*		20.96 (16.73, 25.19)	0.10 (-0.01, 0.21)	0.21 (0.07, 0.35)*		
4-Months Post	14.60 (9.06, 20.14)	0.47 (0.29, 0.64)*		18.80 (14.45, 23.16)	0.27 (0.16, 0.39)*	0.22 (0.04, 0.40)*		
<i>Caregiver</i>								
Baseline	24.19 (19.15, 29.24)			25.55 (20.58, 30.52)				
1- Month Post	20.36 (15.69, 25.02)	0.27 (0.13, 0.40)*		20.92 (16.33, 25.50)	0.34 (0.23, 0.45)*	-0.06 (-0.20, 0.08)		
4-Months Post	22.96 (17.38, 28.54)	0.09 (-0.07, 0.24)		20.80 (15.91, 25.69)	0.35 (0.23, 0.46)*	-0.25 (-0.41, -0.09)*		
<i>Child</i>								
Baseline	59.84 (54.27, 65.40)			58.42 (52.69, 64.15)				
1- Month Post	63.62 (57.80, 69.44)	0.24 (0.12, 0.36)*		62.73 (56.99, 68.47)	0.27 (0.16, 0.39)*	-0.03 (-0.16, 0.09)		
4-Months Post	66.36 (60.42, 72.31)	0.41 (0.25, 0.58)*		64.36 (58.72, 70.00)	0.38 (0.26, 0.50)*	0.04 (-0.14, 0.21)		
<b>Avoidance Coping</b>								
<i>Recipient</i>								
Baseline	13.88 (10.62, 17.14)			13.38 (10.40, 16.37)				
1- Month Post	10.87 (7.37, 14.37)	0.33 (0.19, 0.46)*		13.91 (10.63, 17.19)	-0.06 (-0.17, 0.05)	0.40 (0.26, 0.55)*		
4-Months Post	12.54 (8.93, 16.15)	0.15 (-0.02, 0.31)		13.45 (10.37, 16.54)	-0.01 (-0.12, 0.10)	0.16 (-0.01, 0.33)		
<i>Caregiver</i>								
Baseline	13.44 (10.28, 16.60)			15.62 (12.66, 18.59)				
1- Month Post	13.58 (9.62, 17.54)	-0.02 (-0.15, 0.12)		14.66 (11.22, 18.10)	0.12 (0.01, 0.23)*	-0.13 (-0.27, -0.01)*		
4-Months Post	14.97 (11.64, 18.31)	-0.17 (-0.33, -0.02)*		15.66 (12.60, 18.73)	-0.005 (-0.12, 0.11)	-0.17 (-0.34, -0.01)*		
<i>Child</i>								
Baseline	19.28 (16.30, 22.27)			17.84 (14.69, 20.99)				
1- Month Post	16.36 (12.62, 20.11)	0.34 (0.22, 0.47)*		17.20 (13.67, 20.74)	0.07 (-0.04, 0.19)	0.27 (0.14, 0.39)*		

Outcome [Measures]	Within-Group Effects						Between-Group Effects	
	Intervention (n=31)		Control (n=29)					
	Mean <sup>a</sup> (95% CI)	d (95% CI)	Mean <sup>a</sup> (95% CI)	d (95% CI)			d (95% CI)	
4-Months Post	16.31 (12.81, 19.81)	0.35 (0.19, 0.51) <sup>*</sup>	16.40 (12.82, 19.99)	0.17 (0.05, 0.29) <sup>*</sup>			0.18 (0.02, 0.34) <sup>*</sup>	
<b>Expressiveness</b>								
<i>Recipient</i>								
Baseline	6.22 (5.12, 7.32)		5.81 (4.75, 6.87)					
1- Month Post	6.48 (5.22, 7.74)	0.08 (-0.05, 0.22)	6.00 (4.85, 7.15)	0.07 (-0.04, 0.18)			0.02 (-0.12, 0.16)	
4-Months Post	6.59 (5.44, 7.73)	0.12 (-0.06, 0.29)	5.71 (4.52, 6.89)	-0.04 (-0.15, 0.08)			0.16 (-0.02, 0.34)	
<i>Caregiver</i>								
Baseline	5.51 (4.46, 6.56)		5.97 (4.75, 7.19)					
1- Month Post	5.23 (3.87, 6.58)	-0.09 (-0.23, 0.04)	5.71 (4.36, 7.06)	-0.08 (-0.19, 0.03)			-0.01 (-0.15, 0.13)	
4-Months Post	6.09 (4.65, 7.53)	0.20 (0.04, 0.35) <sup>*</sup>	5.80 (4.43, 7.17)	-0.05 (-0.17, 0.07)			0.24 (0.07, 0.40) <sup>*</sup>	
<i>Child</i>								
Baseline	4.61 (3.44, 5.77)		4.48 (3.26, 5.70)					
1- Month Post	4.97 (3.92, 6.01)	0.11 (-0.01, 0.23)	4.88 (3.95, 5.80)	0.12 (0.01, 0.23) <sup>*</sup>			-0.01 (-0.13, 0.12)	
4-Months Post	5.52 (4.46, 6.58)	0.28 (0.11, 0.44) <sup>*</sup>	4.47 (3.53, 5.41)	-0.003 (-0.12, 0.12)			0.28 (0.11, 0.45) <sup>*</sup>	

Note:

<sup>\*</sup> 95% CI for effect size does not include zero, which is equivalent to  $p < 0.05$ .

<sup>a</sup> Positive effect size reflects the desired therapy.