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Parental Depression and Family Environment Predict Distress in Children Prior to Stem-Cell Transplantation

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Abstract

Objective—To examine parental symptoms of depression, family environment, and the interaction of these parent and family factors in explaining severity of distress in children scheduled to undergo stem cell/bone marrow transplantation (SCT).

Method—A self-report measure of illness related distress, adjusted to reflect the experience of medical diagnosis and associated stressors was completed by 146 youth scheduled to undergo SCT. Measures of parental depressive symptoms and family environment (cohesion, expressiveness, and conflict) were completed by the resident parent.

Results—Parental symptoms of depression, family cohesion, and family expressiveness emerged as significant predictors of child-reported distress. Additionally, significant Parental Depression x Family Cohesion and Parental Depression x Family Expressiveness interactions emerged as predictors of the intensity of the child's distress. When parental depressive symptomatology was high, child distress was high regardless of family environment. However, when parental depressive symptomatology was low, family cohesion and expression served as protective factors against child distress.

Conclusion—Parental depressive symptomatology and family functioning relate to child distress in an interactive manner. These findings inform future directions for research, including interventions for parents aimed at promoting child adjustment during the pediatric cancer experience.

Keywords

childhood cancer; stem cell transplantation; family environment; depression; adjustment

Despite much advancement in medical technologies for children undergoing stem cell or bone marrow transplantation (SCT), the experience remains extremely stressful for many patients, parents, and families.^{1,2} SCT is an effective but high-risk and demanding procedure used increasingly in the treatment of childhood leukemia, as well as other malignancies and serious childhood illnesses. Although SCT remains a risky procedure with a range of possible physical complications, medical advances have decreased mortality rates for children who undergo the

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treatment.¹ With the number of SCT survivors continuing to increase, research has therefore focused on the psychosocial difficulties for children and their families who are undergoing this stressful procedure.²⁻⁵

Given that the most common indications for SCT involve leukemia and other malignancies, the literature regarding psychosocial adaptation to childhood cancers in general provides important background for understanding child adaptation to SCT. Childhood cancers and their treatments are not discrete or uniform experiences. The illness involves a series of distinct stressors (e.g., diagnosis, invasive procedures, hospitalizations) for the child and parent that last for many years. The available research suggests that the majority of children surviving cancer transition out of treatment with relative ease and few symptoms of behavioral or emotional distress,⁶⁻¹⁰ but a small subset may experience higher levels of distress which can compromise both psychosocial and medical outcomes. In order to identify these children and families for targeted prophylaxis or intervention, it is important to understand predictors of their distress. In regard to SCT, the level of psychosocial adjustment of the patient prior to SCT is likely to be an important predictor of longer-term psychosocial adjustment to the experience. Although there is limited data from pediatric settings, research in adult SCT clearly indicates that pre-SCT psychological functioning is predictive of both psychosocial outcomes and medical complications.¹¹⁻¹⁵ Various pre-SCT psychological parameters, including levels of depression and anxiety were found to be markers of poorer prognosis, worse psychosocial outcomes and self-reported quality of life up to a year post-SCT.¹⁶

Based on Bronfenbrenner's social-ecological perspective,¹⁷ research suggests that how children negotiate the various aspects of stressful experiences is influenced by the quality of the social or familial system within which they are embedded. Families of children undergoing SCT are faced with a range of challenges, including confronting their child's mortality and changes in the family system due to the displacement of the child and resident parent.¹⁸ Typically, one parent stays with the child throughout the procedure (i.e., the resident parent), spending a large amount of time with the patient in the hospital away from home, work, and other family members. This can be emotionally stressful for the parent and can strain the family system. The incidence of parental depressive symptomatology in this population has been found to be elevated¹⁹⁻²⁰ and while conflicting results exist regarding family functioning during this time, there is some evidence of increases in family conflict and reductions in the quality of the family environment during and following cancer treatment.²¹⁻²²

A large and growing body of research indicates that when parents are depressed children are at increased risk for a range of social and psychological difficulties.^{23,24} Parents struggling with symptoms of depression may have difficulties remaining responsive to their children.²⁵ Certainly, the mental health of the non-resident parent, as well as other important caregivers may impact child adjustment related to the cancer experience. However, we hypothesize that the mental health of the resident parent may have an even greater impact on child adjustment given the amount of time and relative isolation the pair experiences.

Similarly, the functioning of the family system may greatly impact child adjustment to SCT.²⁶ Studies have supported the importance of family cohesion, expressiveness, and conflict in adapting to stressful experiences.²⁷ Research has indicated that when parents and children are able to talk openly about stressful life events, such as SCT, children experience better short- and long-term emotional adjustment.²⁷⁻²⁹ Holmes and colleagues²⁹ found that when families display strong cohesion and expressiveness, children are more likely to manifest positive adjustment in general and during transitions and times of increased stress. Also, when families are characterized by high levels of conflict, research has shown that children are more likely to experience internalizing and externalizing symptoms, a link which seems to be exacerbated by stressful life experiences in these instances.^{29,30}

The importance of the family environment in the SCT setting has received some empirical support. Family cohesion, expressiveness, and conflict have been shown to predict several child outcomes,²⁷ including social competence, externalizing and internalizing symptoms six-month post-SCT. In particular, family expressiveness and cohesion acted as protective factors against the development of behavioral and psychological problems. In a subsequent study of children undergoing SCT, parental distress was found to intensify the link between a negative family environment and more general indications of child distress (e.g., internalizing symptoms).⁵

In summary, the available data suggests that child adjustment pre-SCT will be an important determinant of their response during the acute phase of the procedure and of longer term psychosocial outcomes. The circumstances of childhood cancer put parents at risk for experiencing depressive symptoms and families at risk for compromised functioning, factors known to be related to child adjustment. Therefore it is important to investigate the interaction of multiple levels of systemic influence in the prediction of child distress at the time they present for SCT. However, there has been little research on the interaction between parent and family influences on child distress in response to SCT. The present study investigated the interaction between parental depressive symptoms and family environment in explaining children's distress at admission for SCT. We hypothesized that the relation between family environment and child distress would differ according to levels of parental depressive symptoms.

Methods

Participants

Participants ($N=146$, 43% girls) were recruited from four children's hospitals across the United States, as part of a larger clinical trial investigating the efficacy of interventions to reduce distress associated with the SCT experience. Patients between the ages of six and eighteen were recruited along with their parents if they were scheduled to undergo SCT. Other eligibility requirements included (1) an anticipated hospital stay of at least three weeks, (2) patient and parent ability to speak English, and (3) parent ability to read English. Additionally, the participating parent was expected to be the primary caregiver for the child during SCT, as well as available for the duration of the transplant hospitalization. A total of 233 parent-child dyads were approached to participate in the study, 78% of whom initially consented. Reasons given for declining to participate included: being uncomfortable with the proposed intervention ($N=6$), child being uninterested ($N=11$), parent being uninterested ($N=2$), difficulty communicating in English ($N=6$), and other reasons ($N=3$).

The 146 participants in the present study represent those who completed all baseline measures (i.e., both parent and child report). The sample had a mean age of 13.2 years (standard deviation=3.7), and self-identified as 78% White, 11% Black/African-American, and 9% of other racial/ethnic backgrounds. Parent report data was collected from resident parents, of whom 82% were the mother of the patient, 12% the father, and 6% another caretaker. Of the reporting mothers and fathers, 68% were married, 14% were single, 8% were divorced, 7% were remarried, and 3% reported other marital statuses. The demographic and medical background of the sample is summarized in Table 1.

Measures

Child Illness-Related Distress—Child symptoms of distress were measured using a modified version of the UCLA Post Traumatic Stress Disorder Index (PTSDI),³¹ a measure of posttraumatic stress symptoms. Although designed to screen for posttraumatic stress disorder (PTSD), most of the items of the PTSDI reflect non-specific symptoms that occur in response to a specified event, and the instrument can be used more generically as a measure of illness

or event-related distress.³² Here it is conceptualized as indicator of illness-related distress. The instrument includes three subscales, representing symptoms of re-experiencing and intrusion, avoidance and numbing, and arousal. In the present study, a 22-item version, identifying a serious illness requiring transplant as the precipitating event was administered as a self-report to participating patients, and total scores were calculated across the three subscales. Total scores for the instrument achieved favorable internal consistency in the current sample ($\alpha = .89$).

Parental Depressive Symptoms—Parental symptoms of depression were assessed with the Center for Epidemiologic Studies Depression Scale (CES-D),³³ a widely used self-report measure of symptoms of depression, including loneliness, sadness, changes in appetite, changes in sleep, and loss of pleasure. This 20-item instrument, ranging from 0 (*rarely or none of the time*) to 3 (*most or all of the time*), was administered to parents as a measure of their own depressive symptoms. Internal consistency in the present set of participants was also favorable ($\alpha = .90$). When used as a screening instrument for depression, a cut-point of 16 is commonly utilized,³⁴ yet parental symptoms of depression were considered a continuous marker of distress in the present study.

Family Environment—The Family Environment Scale (FES)³⁵ is a widely-used measure assessing ten dimensions of family functioning and the home environment. For the present study, the subscales of the relationship domain were administered as a self-report for the resident parent. These subscales include family cohesion (9 items), expressiveness (9 items), and conflict (9 items). All 27 items were answered in a true-false format. The three subscales generated alphas of .60, .54, and .69, respectively.

Results

Descriptive statistics and zero-order correlations between observed variables can be found in Table 2. The mean level of child illness-related distress, as measured by the PTSDI (23.3) fell on the high end of the “mild” category. Approximately 26% did not report even “mild” symptoms (i.e., scores below 12), while 33% fell in the “mild” range. Additionally, 22% reported in the “moderate” range, and 19% reported severe or very severe symptoms. The mean score of parental depressive symptomatology (19.4) was mildly elevated relative to a cut-point of 16 commonly used when screening for depression. There were no significant differences between transplant-type groups (autologous vs. allogeneic; all $ps > .26$) or gender of the child (all $ps > .18$) on any of the distress measures.

Child age was significantly correlated with severity of parental depressive symptoms, with parents of younger children reporting greater depressive symptoms. Additionally, child-reported distress and parental depressive symptoms were positively correlated, and parental depressive symptoms were negatively correlated with levels of family cohesion and expressiveness and negatively related to family conflict. Of the three dimensions of family environment, severity of child distress was significantly correlated with family expressiveness, with children in more expressive families endorsing less illness-related distress.

Multiple regression analyses were conducted to further explore the relations between family environment, parental depressive symptoms, and child illness-related distress. Child age, family SES,³⁶ and months since diagnosis were entered into all regression analyses as covariates. To examine possible main effects, family cohesion, expressiveness, conflict and parental depressive symptoms were first entered in a regression equation with the three covariates to predict intensity of child distress. In this regression analysis, parental depressive symptomatology was the only factor to explain unique variance in levels of child distress ($\beta = .26, p < .01$).

Next, interaction terms were computed in order to test whether parental depressive symptomatology moderated the relation between any aspects of family environment and intensity of child distress. As a way of reducing possible multicollinearity among the variables, interaction terms were computed using z-scores of all component variables. Three separate regressions were examined with these interaction terms - for family cohesion, family expressiveness, and family conflict. Results from these regression analyses are presented in Table 2. In the first regression, a significant interaction was found between family cohesion and parental depression, ($p=.02$). In the second regression, a significant interaction was found between family expressiveness and parental depressive symptomatology, ($p=.03$). In the third regression, we failed to find an interactive association between family conflict and parental depressive symptomatology in significantly accounting for differences in illness-related distress among the children, ($p=.69$). In other words, parental depressive symptomatology was shown to significantly moderate the relation between family cohesion and child distress, as well as family expressiveness and child distress. Further analyses were completed in order to characterize how parental depressive symptomatology moderates these relations.

Family Cohesion

Procedures to probe the interaction between family cohesion and parental depression were based on Aiken and West's recommendations.³⁷ Two new regressions were performed using high and low probes of parental depressive symptomatology in order to complete a test of simple slopes. For families with high parental depressive symptomatology, severity of child distress did not vary according to family cohesion ($r=.08$, $p=.44$). Conversely, for families with low parental depressive symptomatology, severity of child distress did vary according to family cohesion ($r=-.29$, $p<.05$). As depicted in Figure 1, there was a statistically significant negative relation between family cohesion and child distress only when parental depressive symptomatology was low. When parental depressive symptomatology was low, greater family cohesion was associated with lower levels of child distress. However, at high levels of parental depressive symptomatology, family cohesion did not significantly impact child distress.

Family Expressiveness

Similar results were found when probing the interaction between family expressiveness and parental depressive symptomatology. Two additional regressions were performed using high and low probes of parental depressive symptoms. For families with high parental depressive symptomatology, severity of child distress and family expressiveness were not significantly related ($r=.12$, $p=.34$). Yet, for families with low parental depressive symptomatology, severity of child distress was significantly related to family expressiveness ($r=-.21$, $p=.05$). As was the case with family cohesion, there was a statistically significant relation between family expressiveness and child distress only in the context of low parental depression. These relations are shown in Figure 2.

Discussion

The primary goal of the present study was to investigate the interplay between parental depressive symptoms and factors related to the quality of the family environment in explaining illness-related distress in children undergoing SCT. Because patient distress levels pre-SCT have been related to poorer outcomes for survivors, this study assessed parent, family, and child patient variables prior to SCT. Results indicated that parental depressive symptomatology moderated the relations between family cohesion and child distress and family expressiveness and child distress. Results failed to demonstrate significant direct or interactive effects for family conflict and child distress. This study adds to the current literature regarding family influences on child adjustment to the cancer and pediatric illness experience. Recent research related to the pediatric cancer experience in general has focused on systemic influences on

children's psychological adjustment, as well as interactions among multiple family systems.^{5, 26,38} From a social ecological perspective, the present results underscore the relevance of focusing on the functioning of familial systems in conceptualizing children's adjustment to the SCT experience, including pre-SCT distress.⁵ This study adds to the growing body of evidence that beyond the overall impact of parent and family functioning, the interplay between these factors also has important implications for children's adjustment.

The current findings indicate that in the context of low parental depressive symptoms family cohesion and family expressiveness act as protective factors against child distress related to their illness. Yet, in the context of high parental depressive symptoms, these family factors do not have significant relations to child distress, and children report higher levels of distress regardless of the quality of the family environment. When parental depressive symptoms are low, having a family that is cohesive and expressive appears to buffer children from exhibiting symptoms of distress. However, in situations in which a parent is struggling with symptoms of depression, quality of the family environment does not appear to serve such a protective function. Although the majority of research understanding family influences on child adjustment as focused on influence being exerted from the parents to the child, it is also accepted that many aspects of a child's behavior, temperament, and distress can have effects on parents and family systems.^{39,40} So, it is possible that children who were more distressed in general or specifically by the cancer experience put a larger emotional strain on their resident parent which resulted in the parental expression of depressive symptoms. In order to disentangle the apparent interplay between parental depression and family cohesion and expressiveness in relation to severity of symptoms in children undergoing SCT, as well as to understand how these factors relate to child outcomes post-SCT, a prospective longitudinal investigation would be necessary. Nonetheless, we believe that the current results have important implications for research and clinical work with children and families beginning the SCT experience.

The results of the present study highlight the importance of looking at parent and family influences in conjunction with one another. Had only the main effects of family environment and parental depression been examined, an important aspect of the influence of the family on child adjustment would have been missed. From a practical perspective, these results indicate that children benefit from a cohesive and expressive family environment when their parents are maintaining healthy levels of psychological functioning (e.g., parental depression is low) and the family environment includes high cohesion and expressiveness. Yet, when one or both of these factors is missing or becomes compromised, children become vulnerable to higher levels of distress.

Consistent with other research, the distress reported by patients was generally mild. Given that the time of admission for transplant is typically found to be the most stressful phase of the procedure,^{5,41} the low levels of distress are striking. Nevertheless, 20% of children did endorse problematic levels of symptoms (i.e., "severe" or "very severe"), which underscores the need to identify factors characterizing those children who do not fare as well emotionally before, during, and after SCT. While the present study highlighted the importance of including parent and family factors when understanding child illness-related distress, many other factors, such as dispositional and personality characteristics, are important as well. In contrast to the children, parental depression scores were moderately elevated. Over half of the parents met or exceeded the commonly used criterion for clinical levels of depression. This supports the idea that the time of admission for SCT is extremely stressful for parents, and that parents may be more vulnerable to psychological difficulties than their children. Yet, more research is needed to understand which parents are at highest risk for experiencing depressive symptomatology during this time, and how to best support parents at time of SCT admission and throughout the SCT process.

The present study had several limitations. As highlighted already, all measures were collected simultaneously, so no definitive conclusions can be drawn regarding the temporal relations between these variables. Also, no measure of disease severity was included. SCT is a high risk procedure that is not standard treatment for most children with cancer. Yet, within this subset, there is also a range of disease severity. In the present study, only type of illness was collected, and although measures of distress may include aspects of disease severity, self-reported cancer-related distress was the outcome of interest so no indicator of disease severity was available. Future research would extend knowledge in this area by having medical professionals rate objectively the severity of the illnesses children have that are being treated with SCT.

Additionally, all measures were self-reported. Future research would benefit by assessing aspects of family functioning observationally. For instance, it may be valuable to compare general measures of the family environment (i.e., the FES) and aspects of the family environment more specific to the childhood cancer experience. This could include observational coding of behaviors and conversations between parents and children regarding the cancer treatment and associated experiences. Due to the unique challenges associated with SCT (e.g., physical separation), assessment tools used in the general population may be less relevant, and may be missing some aspects of family functioning that are important during this time. Additionally, the present study was limited by only having one parent report on depressive symptoms. Even though the resident parent likely spends more time with the child currently, the non-resident parent undoubtedly is still important in the child's social ecology. Further, the parent who becomes the resident parent is likely not randomly chosen of the two parents, but is chosen for a number of reasons. For example, families may choose the parent who is more psychologically able to deal with the stress of having a child with cancer, which would make the sample in the present study report less depressive symptoms than representative of the parental unit. Alternatively, the family may choose the parent who holds less financial responsibility in the household inasmuch as their time spent away from a job and in the hospital would not add an additional strain to the family. For this reason, a necessary extension of the present study would include all important caregivers to the child as possible influences on adjustment.

In spite of these limitations, there are several clinical implications of the current findings. First, interventions aimed at increasing open communication between parents and children, as well as increasing bonding between all members of the family may be in the best interest of the child's adjustment to SCT. Yet, such interventions may not be successful in the context of high parental depression. In these cases family interventions may actually increase negative communication patterns and emotional fusion characteristic of families with a depressed parent.²⁵ Hence, in situations involving a depressed parent, clinicians may do well to focus initially on intervening with the individual parent and providing the necessary support to improve his or her functioning. Once the parent achieves a greater sense of stability, interventions may be more effectively focused on family expressiveness or cohesion, depending on the needs of the particular resident parent-patient dyad. Indeed, recent research has shown that treatment of parental symptoms can decrease child symptoms.^{42,43} Clinical work with children undergoing SCT and their families will also benefit from attending to multiple levels of systemic influence in assessment and possible intervention with patients and their family members.

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Figure 1.
Probing of Interaction between Family Cohesion and Parental Depression

Figure 2.
Probing of Interaction between Family Expressiveness and Parental Depression

Table 1

Demographic and Medical Background

	n	%
Child's Sex		
Male	83	56.8
Female	63	43.2
Child's Race/Ethnicity		
White	112	76.7
Black/African-American	17	11.6
Other	17	11.6
Resident Parent		
Mother	119	81.5
Father	18	12.3
Other	9	6.2
Diagnosis		
ALL	40	29.6
AML	36	26.6
Other leukemia	13	9.6
Hodgkins lymphoma	6	4.4
NHL	9	6.6
Neuroblastoma	5	3.7
Other solid tumor	6	4.4
Nonmalignancy	14	10.4
Myelodysplastic Syndrome	6	4.4
Type of Transplant		
Allogeneic		
Matched sibling	40	27.4
Other allogeneic	78	53.4
Autologous	28	19.2

ALL=Acute Lymphoblastic Leukemia; AML=Acute Myeloid Leukemia; NHL= Non-Hodgkins' Lymphoma.

Table 2
Descriptive Statistics and Zero-order Correlations among Study Measures

	1.	2.	3.	4.	5.	6.	7.	8.
1. Child's Age	-							
2. Months since Diagnosis	.02	-						
3. Family SES	.11	-.03	-					
4. Child Distress (c)	-.04	.07	-.08	-				
5. Parental Depression (p)	-.22**	-.11	.03	.29***	-			
6. Family Cohesion (p)	.02	.08	-.02	-.12	-.27***	-		
7. Family Expressiveness (p)	-.07	-.11	-.04	-.17*	-.31***	.44***	-	
8. Family Conflict (p)	-.04	-.04	-.09	.09	.23**	-.54***	-.17*	-
Mean	13.22	25.79	2.41	23.33	19.37	7.34	5.70	2.64
Standard Deviation	3.67	38.04	1.10	14.55	10.74	1.63	1.86	1.97

Note. c = child self-report, p = parent self-report

* p<.05

** p<.01

*** p<.001.

Table 3
Regression Analyses Predicting Child-Reported Distress

Predictor	B	SE	β
1. Family Cohesion			
Child Age	.22	.35	.06
Months Since	.06	.03	.14
SES	-.63	1.15	-.05
FES Cohesion	-.52	.87	-.06
Parental CES-D	.48	.13	.35***
CES-D * Cohesion	.15	.07	.21*
1. Family Expressiveness			
Child Age	.24	.35	.06
Months Since	.04	.04	.11
SES	-.53	1.17	-.04
FES Expressiveness	-.48	.71	-.06
Parental CES-D	.44	.13	.32**
CES-D * Expressiveness	.12	.06	.19*
1. Family Conflict			
Child Age	.27	.35	.07
Months Since	.05	.04	.13
SES	-.88	1.17	-.07
FES Conflict	.10	.67	.01
Parental CES-D	.43	.13	.32**
CES-D * Conflict	-.03	.07	-.04

Note. CES-D = Center for Epidemiological Studies-Depression

†
p<.10

*
p<.05

**
p<.01

p<.001.