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Psychological Distress and Psychiatric Diagnoses among Primary Caregivers of Children undergoing Hematopoietic Stem Cell Transplant: An Examination of Prevalence, Correlates, and Racial/Ethnic Differences

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Abstract

Objective—The aims of the study were to examine the prevalence of self-reported psychological distress, examine the prevalence of interview-rated psychiatric diagnoses, identify correlates of psychological distress and psychiatric diagnosis, and examine racial/ethnic group differences on measures of psychological distress among primary caregivers of children preparing to undergo hematopoietic stem cell transplant (HSCT).

Methods—Caregivers (N = 215) completed the Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI), Impact of Events Scale (IES), and a psychiatric interview assessing major depressive disorder (MDD), generalized anxiety disorder (GAD), and panic disorder (PD).

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Regression analyses examined correlates of distress and psychiatric diagnosis. Comparisons were made between racial/ethnic groups.

Results—Posttraumatic stress symptoms were reported by 54% of caregivers during the time preparing for the child's HSCT. Twenty-seven percent of caregivers met diagnostic criteria for at least one of the psychiatric diagnoses during this time. Few factors were associated with distress or psychiatric diagnosis, except the child scheduled for allogeneic transplant, being married, and prior psychological/psychiatric care. Socio-demographic factors accounted for racial/ethnic group differences, except Hispanic/Latino caregivers reported higher BDI scores than non-Hispanic White caregivers.

Conclusion—Caregivers may be at greater risk of posttraumatic stress symptoms than anxiety or depression. Prior psychological/psychiatric treatment is a risk factor for greater psychological distress and psychiatric diagnosis during this time. Racial differences are mostly due to socio-demographic factors.

Keywords

pediatric transplant; parent; caregiver distress; psychiatric diagnoses

1. Introduction

Pediatric hematopoietic stem cell transplant (HSCT) is used to treat children with various hematologic, oncologic, and metabolic diseases. While the treatment can be life-saving, it is also physically and psychologically demanding for both the child and their caregiver. HSCT involves preparatory regimens of chemotherapy and/or radiation, prolonged hospital stays, and a high risk of death and other medical complications, such as infection, following the transplant [1,2]. Children may experience long-term effects such as infertility, social and academic problems, increased risk of secondary malignancies and late medical effects, and potential disease recurrence [3,4]. The HSCT experience is also difficult for the primary caregiver, traditionally the biological parent, who provides ongoing practical and emotional care for the ill child whilst balancing family, household, and/or occupational responsibilities [5].

Given the stressors that primary caregivers face, it is not surprising that they report elevated levels of psychological distress on self-report measures of depressive symptoms [6,7,8] and anxiety symptoms [7,8] during the time period immediately preceding their child's HSCT. In addition, structured interviews indicate that a significant subset are diagnosed with clinical depressive disorder [9–11] anxiety disorders [9–11] and adjustment disorder [11]. A recent review highlighted limitations in the literature to draw conclusions about psychological distress among primary caregivers [12]. The first issue regards the lack of consistency with regard to measures used across studies. Studies did not utilize consistent measures of psychological distress [7, 13–14]. This lack of consistency results in wide variability in prevalence estimates of psychological distress. The second issue is that studies utilize measures without clinical cut-offs or established norms [15]. A third limitation is that studies did not assess psychological distress responses unique to the HSCT experience [9, 14]. A key response to a difficult life event, such as a child's illness, is posttraumatic stress

symptoms, which are psychological and physiological reactions such as intrusive thoughts and avoidance. Parents of children diagnosed with cancer report high levels of posttraumatic stress symptoms [16, 17].

Reviewing the literature indicates additional limitations than those noted in the review [9]. An additional issue is the majority of studies rely upon self-report measures and have not utilized clinical diagnostic techniques, such as the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders (SCID) [18], thus not providing information about psychiatric diagnoses. The few studies that have utilized the SCID are limited by small sample sizes [9]. Finally, prior work is limited by the lack of diversity with regard to socio-demographic and racial/ethnic characteristics. Most samples consist of married [9, 13] well-educated [6,13], and Caucasian parents [9, 12]. Since socio-demographic characteristics can play an important role in psychological distress and disorders [19,20], it is important to examine psychological distress in a more heterogeneous sample.

The current study addressed these limitations by examining psychological distress utilizing self-report measures with established clinical cut-offs, a structured clinical diagnostic interview, and including a more racial/ethnic diverse caregiver population. The study had four aims. The first study aim was to examine the prevalence of psychological distress utilizing three self-report measures, the Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), and Impact of Events Scale (IES) and to evaluate co-morbidity. The second study aim was to examine the prevalence of depression and anxiety disorders utilizing a clinical diagnostic interview (SCID) and to evaluate co-morbid diagnoses. We hypothesized that the prevalence of depressive symptoms, anxiety symptoms, and posttraumatic stress symptoms and SCID diagnoses would be comparable to prior studies. We hypothesized that elevated levels of posttraumatic stress symptoms would be more common than depressive symptoms and anxiety symptoms given the stress associated with the HSCT experience. The third study aim was to examine demographic, medical, and psychological/psychiatric care utilization variables associated with psychological distress and receiving a diagnosis. We hypothesized that greater depressive symptoms, anxiety symptoms, and posttraumatic stress symptoms and receiving one of the three SCID psychiatric diagnoses would be associated with younger caregiver age and the receipt of prior psychological care, which is consistent with prior findings [9, 10]. The final study aim was to examine racial/ethnic group differences on measures of depressive symptoms, anxiety symptoms, and posttraumatic stress symptoms and receiving a SCID diagnosis across the three groups represented in the sample, Hispanic/Latino, non-Hispanic White, and non-Hispanic Black caregivers. We hypothesized that racial/ethnic differences would be accounted for by socio-demographic factors, which has been supported in prior research with different populations [19,20].

2. Methods

2.1. Participants

The present study utilized baseline data from an ongoing, multi-site randomized clinical trial (RCT) evaluating the efficacy of a Parent Social-Cognitive Processing Intervention Program

(P-SCIP) compared with best recommended psychosocial care (BPC). The P-SCIP intervention consisted of five one-hour sessions conducted post-HSCT. The sessions included material on problem-solving skills, communication skills, relaxation skills, and managing child behavioral problems during HSCT (unpublished data). Recruitment for the RCT occurred between October 2008 and January 2014. Study sites were located in the northeast, southeast, and western United States. Inclusion criteria for the randomized trial were: 1) participant was the primary caregiver (e.g., mother, father, grandparent, foster parent) of a child scheduled for HSCT within a month; 2) primary caregiver was 18 years; 3) the child undergoing HSCT was 18 years; 4) the child did not have a diagnosis of medulloblastoma or other cancer of the brain (due to cognitive issues these children experience); 5) participant had phone service (due to follow-up assessments for the clinical trial being administered via telephone) and; 6) participant spoke, read, and wrote English or Spanish.

2.2. Procedure

The sample and recruitment method is similar to previous studies of this population [9, 10]. The research study assistant or principal investigator at each site identified eligible caregivers during the consultation preparing for HSCT. Interested caregivers completed a written informed consent document approved by the Institutional Review Board at each site. Participants completed a baseline paper-and-pencil questionnaire and scheduled a time with the research assistant to complete the SCID modules during the week preceding the HSCT. During the week preceding HSCT the child is admitted to the inpatient hospital, undergoes a number of medical tests, and receives preparatory regimens of chemotherapy and/or radiation. For Spanish-speaking participants, materials were translated into Spanish using a double translation approach, which involved one translator translating the materials from English to Spanish and second translator translating back to English. Both versions were then examined for inconsistencies. The clinical interview was also conducted in Spanish. Due to the availability of Spanish-speaking research study staff, Spanish-speaking only participants were recruited from only one site.

2.3. Measures

2.3.1. Demographics variables—Demographic data on the baseline survey included caregiver age, relationship to the child, race/ethnicity, marital status, education, income, child age, child gender, and number of additional children.

2.3.2. Medical variables—Medical chart review captured child diagnosis (cancer/non-cancer), type of HSCT (autologous vs. allogeneic), relationship to donor, and time to find a HSCT donor.

2.3.3. Beck Depression Inventory (BDI)—The BDI [21] is a 21-item scale that is widely-used to assess emotional, cognitive, and somatic symptoms of depression. The scale has demonstrated strong psychometric properties and internal consistency in prior work with this population [9]. In the current study $\alpha = .86$.

2.3.4. Beck Anxiety Inventory (BAI)—The BAI [22] is a 21-item scale used to assess anxiety symptoms. The scale has demonstrated strong psychometric properties in prior work with this population [9]. In the current study $\alpha = .90$.

2.3.5. Impact of Events Scale (IES)—The IES [23] was used to measure posttraumatic stress symptoms. It is a 15-item self-report scale that assesses intrusive thoughts and avoidant behaviors related to the child's HSCT. Caregivers rated symptoms on a 5-point Likert scale (0 = *not at all*; 5 = *often*). The measure has been widely used to assess posttraumatic stress symptoms in various health populations [24,25] and has demonstrated adequate psychometric properties with this population [10]. In the current study $\alpha = .92$.

2.3.6. Structured Clinical Interview for DSM Disorders (SCID)—The SCID is a semi-structured clinical interview that provides a clinical diagnosis according to the Diagnostic and Statistical Manual of Mental Disorder [16]. The major depressive disorder (MDD), generalized anxiety disorder (GAD), and panic disorder (PD) modules were administered by research assistants. The research assistants were trained by a licensed psychologist and expert in the SCID (JR). Ongoing training and supervision was provided. To establish inter-rater reliability, the expert reviewed a random selection of 73 (34%) audiotapes of the SCID administration. The kappa coefficients were .74 for MDD, .75 for GAD, and .66 for PD, indicating good inter-rater reliability [26].

2.3.7. Prior and current utilization of psychological/psychiatric care—Prior utilization was assessed by four questions that asked whether the caregiver had ever sought professional counseling, sought treatment for drug or alcohol problems, been hospitalized for psychological problems, or taken medication to help with mood. A dichotomous variable was computed indicating prior utilization of psychiatric care (yes/no). Current utilization was assessed by four questions that asked whether the caregiver had seen a religious counselor, psychologist or psychiatrist, social worker to discuss emotional concerns, or attended a support group in the past month. A dichotomous variable was computed indicating utilization of psychosocial care in the past month (yes/no). This method of assessing prior and current use of psychological and/or psychiatric care has been used in prior research with this population [9].

2.4. Statistical analysis plan

Data were analyzed utilizing Statistical Packages for Social Sciences (SPSS). Two participants did not complete the IES, one did not complete the BDI, and one did not complete the BAI. These cases were not included in analyses including that measure. To address the first study aim, we calculated descriptive analyses for the BDI, BAI, and IES. The clinical categories recommended by the scales' developers [21, 22] and used in prior research with this population [9] were utilized for the BDI and BAI: scores < 10 = *none or minimal symptoms*, 10–18 = *mild*, 19–29 = *moderate*, and 30–63 = *severe*. The IES cut-off for clinically-significant symptoms (≥ 26) was utilized [23]. This cut-off has been utilized with relatives of medically-treated patients [27]. Correlational analyses were conducted to assess co-morbid depressive symptoms, anxiety symptoms, and posttraumatic stress symptoms. To address the second study aim, we calculated the frequency of caregivers

receiving a diagnosis on each of the three modules of the SCID (i.e., MDD, GAD, and PD), the frequency of co-morbid diagnoses, and the frequency of caregivers receiving at least one SCID diagnosis. To address the third study aim, we conducted separate multiple regression analyses of BDI, BAI, and IES scores. Logistic regression was utilized for SCID diagnoses. A dichotomous variable was created that indicated whether the caregiver received a diagnosis on any of the three diagnostic modules. This procedure was done due to the small number of cases of each diagnosis and evidence of co-morbidity (19/58 caregivers had > 1 diagnosis). For all regression analyses, demographic predictor variables included caregiver age, relationship to patient (mother vs. other), marital status (married vs. not), household income, education, number of additional children, and child gender. Medical variables included child diagnosis (cancer vs. non-cancer), type of transplant (autologous vs. allogeneic), and time to find a donor. To address the fourth study aim, two separate analysis steps were taken. First, ANOVA analyses compared non-Hispanic Whites ($n = 103$), non-Hispanic Blacks ($n = 57$), and Hispanic/Latino ($n = 30$) caregivers on BDI, BAI, and IES. Chi-square analyses compared groups on receiving one of the three SCID diagnoses. These racial/ethnic groups were the three most represented groups in the total sample. Together, the other groups comprised 12% of the total sample and thus were too small for comparative analyses. Second, regression analyses were conducted to look at the impact of racial/ethnic group while including covariates. Regression analyses were conducted including variables statistically associated with depressive symptoms, anxiety symptoms, and posttraumatic stress symptoms, variables that statistically differed between groups, and income and education, due to research suggesting that these socio-demographic factors play a role in racial/ethnic differences [28].

3. Results

3.1. Sample description

Of the 386 eligible caregivers approached for the clinical trial, 146 caregivers (37.8%) declined participation, 12 caregivers (3%) consented but withdrew before completing baseline questionnaires and SCID interview, and 13 caregivers (3%) were lost to follow-up. Two hundred fifteen caregivers (55.7%) consented, completed baseline questionnaires and the SCID interview, and were included in this study. The majority of study refusers did not provide a reason. Among those that did, lack of interest in the research (31%) and feeling too overwhelmed/stressed/tired (20%) were the most common reasons. Comparisons between study participants and refusers on available data (age, race, marital status, child gender, child age) indicated that participants were older than non-participants [$t(347) = -2.56, p = .003, M_{\text{participants}} = 37.4$ years, $M_{\text{refusers}} = 32.9$ years]. Individuals who identified as Hispanic/Latino were more likely to participate than individuals who identified as non-Hispanic/Latino [$\chi^2(1, n = 345) = 5.99, p = .014$]. The participation rates were significantly higher at two sites (63% and 71%) when compared with a third site (48%) [$\chi^2(2, n = 334) = 11.79, p = .003$].

The final sample consisted of 215 primary caregivers. The majority of the sample was mothers (88%), married (69%), and had at least some college education (74%). The racial/ethnic distribution was 48% non-Hispanic White, 26% non-Hispanic Black, 14% Hispanic/

Latino, 12% other ethnic groups. Twelve caregivers (6%) completed the measures and interview in Spanish. The children receiving HSCT were diagnosed with cancer (51%) and other medical conditions requiring HSCT (49%). The average time to find an HSCT donor was three months. The majority of children were scheduled to undergo allogeneic transplant (80%). Full demographic and medical data is presented in Table 1.

3.2. Psychological distress: BDI, BAI, and IES scores

The average score on the BDI ($M = 11.7$, $SD = 7.8$) and BAI ($M = 11.5$, $SD = 9.8$) was in the mild range. Thirty-four caregivers (16%) reported BDI scores in the moderate or severe ranges. Forty-six caregivers (21%) reported BAI scores in the moderate or severe ranges. The average score on the IES was in the clinically significant range ($M = 31.3$, $SD = 22.5$). One hundred and sixteen caregivers (54%) reported scores above the clinical cut-off (> 26). In terms of co-morbidity, there was a strong association between all three measures. BDI scores were correlated with BAI ($r = .62$, $p < .001$) and IES ($r = .55$, $p < .001$) scores. BAI and IES scores were correlated ($r = .56$, $p < .001$).

3.3. Psychiatric Diagnosis: MD, GAD, and PD diagnoses

Fifty-eight caregivers (27%) received at least one of the three diagnoses (MDD, GAD, or PD) on the SCID. Thirty-eight caregivers (18%) met criteria for MDD, thirty-three (15%) for GAD, and seven (3%) for PD. Of the 58 caregivers who received a diagnosis, nineteen (32.7%) had co-morbid diagnoses. Fifteen caregivers were diagnosed with MD and GAD, three with MD, GAD, and PD, and one caregiver with MD and PD.

3.4. Correlates of psychological distress and psychiatric diagnosis

Higher BDI scores were significantly associated with prior psychological/psychiatric care [$\beta = .19$, $t(204) = 2.41$, $p = .017$]. Higher BAI scores were associated with prior psychological/psychiatric care [$\beta = .22$, $t(204) = 2.89$, $p = .004$]. Higher IES scores were associated with being married [$\beta = .17$, $t(202) = 2.02$, $p = .045$] and having a child preparing to undergoing allogeneic HSCT [$\beta = .18$, $t(202) = 2.31$, $p = .022$]. Prior psychological/psychiatric care was associated with receiving at least one SCID diagnosis [$\chi^2 = 7.43$, $p = .003$]. Regression analyses are in Table III.

3.5. Racial/Ethnic group differences

First, initial comparisons were made between the groups on the demographic, medical, and psychological/psychiatric care utilization variables. There were racial/ethnic group differences regarding marital status [$\chi^2 (2, n = 184) = 15.33$, $p < .001$], household income [$\chi^2 (2, n = 178) = 17.74$, $p < .001$], education [$\chi^2 (2, n = 185) = 10.21$, $p = .006$], child diagnosis [$\chi^2 (2, n = 185) = 7.26$, $p = .026$], and prior psychological/psychiatric care [$\chi^2 (2, n = 184) = 12.24$, $p = .002$]. Non-Hispanic White caregivers were more likely to be married, report household income greater than \$49,000, have a child diagnosed with cancer, and report prior psychological/psychiatric care. Hispanic/Latino caregivers were less likely to have completed at least some college. These variables were included in subsequent regression analyses. There were no significant differences between Spanish-speaking and English-speaking caregivers.

Second, the total scores on the BDI, BAI, and IES were compared between the three groups (See Table IV). Post-hoc analyses revealed that Hispanic/Latino caregivers reported significantly higher BDI scores than non-Hispanic White ($p = .026$) and non-Hispanic Black ($p = .013$) caregivers and Hispanic/Latino caregivers reported significantly higher IES scores than non-Hispanic Black caregivers ($p = .009$). There were no significant group differences on BAI scores [$F(2, 183) = 2.75, p = .067$] or SCID diagnosis [$\chi^2(2, n = 192) = 3.31, p = .192$].

Finally, regression analyses examined the racial/ethnic group differences on the BDI and IES controlling for the factors that statistically differed between groups (i.e., marital status, income, education, child diagnosis, prior psychological/psychiatric care). Identifying as Hispanic/Latino (vs. non-Hispanic white) remained statistically associated with higher BDI scores [R^2 change = .05, $F = 6.38, p = .013$]. Identifying as Hispanic/Latino (vs. non-Hispanic Black) was no longer statistically associated with higher BDI scores [R^2 change = .041, $F = 3.39, p = .07$]. Identifying as Hispanic/Latino (vs. non-Hispanic Black) was no longer statistically associated with higher IES scores [R^2 change = .045, $F = 3.74, p = .057$].

4. Discussion

This study examined prevalence, demographic and medical correlates and racial/ethnic differences with regard to psychological distress and psychiatric diagnoses among primary caregivers of children preparing to undergo HSCT participating in a larger multi-site study. There were important novel findings in terms of the prevalence/comorbidity of depressive symptoms, anxiety symptoms, and posttraumatic stress symptoms, the prevalence/comorbidity of SCID diagnoses, the demographic and medical correlates, and racial/ethnic group differences. These findings are discussed in the context of prior research and possible clinical implications.

In terms of the first study aim, there was a high prevalence of posttraumatic stress symptoms compared with anxiety and depressive symptoms. The finding is consistent with our hypothesis. There was a relatively low prevalence of depressive (16%) and anxiety (21%) symptoms in the moderate and severe ranges. These figures are much lower than the 35% to 66% rates reported in prior work with smaller samples [7, 13–14], but consistent with prior studies with more comparable sample sizes [9,10]. In contrast, more than half of caregivers reported clinically-significant posttraumatic stress symptoms. The prevalence is consistent with studies of parents of childhood cancer survivors [16–17, 29]. It is important to note that there was no difference in posttraumatic stress symptoms between caregivers of a child diagnosed with cancer and those without a cancer diagnosis. This finding suggests that the posttraumatic stress symptoms are not solely a reflection of psychological distress related to having a child with cancer. In addition to posttraumatic stress symptoms among caregivers of children diagnosed with cancer [16–17], there is evidence among caregivers of children with Type 1 diabetes [30] and severe burns [31], suggesting that this reaction may be common among caregivers of medically-ill children. Posttraumatic stress symptoms tap into psychological distress symptoms specific to the traumatic event, in this case having a child undergoing HSCT. While parents may not experience significant symptoms of global distress, such as depressive symptoms or anxiety, they may still be having difficulty coping

with the experience of having a child undergo this experience, which may manifest in cognitive and behavioral efforts to avoid reminders of the HSCT and intrusive thoughts about it. There was high correlation between the self-report measures of depressive symptoms, anxiety symptoms, and posttraumatic stress symptoms. The high correlation between the BDI and BAI is consistent with prior studies with this population [9] and prior use of these measures among outpatient psychiatric samples [32]. There is also evidence that global distress, such as anxiety and depression [33] is a risk factor for developing posttraumatic stress symptoms [34], which may account for the correlation between the IES and BDI/BAI scores.

In regard to the second study aim, approximately one-quarter (27%) of caregivers received at least one SCID diagnosis. The most common diagnosis was MDD, which was closely followed by GAD. Very few caregivers met diagnostic criteria for PD. These findings are consistent with a prior study with a smaller sample size [9]. The findings suggest that a significant proportion of caregivers meet diagnostic criteria for a psychiatric disorder that may warrant psychiatric treatment. Since the entire SCID was not administered, this figure may not take into account additional or pre-existing psychiatric disorders (e.g., adjustment disorder, substance abuse disorders) and the reported prevalence may be an underestimate of the total prevalence. There was strong evidence of co-morbidity, with 28% of the caregivers who received a diagnosis meeting criteria for another diagnosis, consistent with prior studies with this population [9]. Given the high levels of co-morbidity, our results suggest that a subset of caregivers are at particular risk and may benefit from clinical intervention during this time period.

In regard to the third study aim, there were relatively few demographic or medical variables associated with depressive symptoms, anxiety symptoms, or posttraumatic stress symptom, or receiving one of the SCID diagnoses. The only three significant variables associated were being married, having a child undergoing allogeneic transplant, and prior utilization of psychiatric/psychological care. First, being married was associated with higher IES scores, but not BDI/BAI scores nor receiving a SCID diagnosis. The findings regarding marital status and BDI, BAI, and receiving a diagnosis are consistent with prior work [9]. The fact that marital status was associated with IES scores was not consistent with our hypotheses and is a unique finding that is difficult to interpret. While many studies have not found an association between marital status and posttraumatic stress among parents of children diagnosed with cancer [35], there has been an association between marital status and posttraumatic stress symptoms among mothers of premature infants [36]. However, no explanation was offered in regard to that finding. There is evidence that some married couples experience negative relationship changes when a child is diagnosed with cancer [37]. It is possible relational stress or the experience of the caregiver present with the child at the hospital during the time preparing for HSCT as the 'lone' parent may influence posttraumatic stress symptoms. Marital status was only associated with posttraumatic stress symptoms and conclusions cannot be drawn about the impact on depressive or anxiety symptoms. Further research assessing contributors to these differences, such as relationship satisfaction and available versus expected support is needed to better understand this finding. Factors that were not assessed, such as marital discord, may play a role in this relationship. Second, we found that caregivers whose child was preparing to undergo an

allogeneic transplant reported higher IES scores, but not higher BDI/BAI scores nor receiving a SCID diagnosis. Allogeneic transplant is associated with greater medical complications and risk of mortality [38, 39]. Given this knowledge, caregivers of children undergoing this type of transplant may experience intrusive thoughts and/or avoidant behaviors regarding HSCT. Third, as expected, prior utilization of psychological/psychiatric care was significantly related to BDI/BAI scores and receiving a SCID diagnosis. Caregivers with a history of psychological distress may be particularly vulnerable during this stressful time period.

The remaining demographic and medical factors were not significant correlates. Contrary to our hypothesis, younger age was not associated with greater depressive symptoms, anxiety symptoms, or posttraumatic stress symptoms, nor receiving a SCID diagnosis. While prior studies have noted higher psychological distress among younger caregivers [9,10], the findings are not consistent with some studies reporting that age was not associated with posttraumatic stress symptoms [40]. Demographic factors, such as household income, caregiver education, child gender, and number of additional children, were not associated with depressive symptoms, anxiety symptoms, or posttraumatic stress symptoms, nor receiving a SCID diagnosis. The findings suggest that having a child under HSCT may be universally stressful for caregivers, regardless of many demographic factors that have been associated with increased risk for psychological distress. Medical factors, such as child diagnosis (cancer vs. non-cancer) and time to find a donor, were not associated with depressive symptoms, anxiety symptoms, or posttraumatic stress symptoms, nor receiving a SCID diagnosis. The lack of difference between caregivers of children diagnosed with cancer versus other diagnoses requiring HSCT suggests that psychological distress may not be specific to the illness, but rather the HSCT experience. Since the assessment took place during the time preparing for HSCT, a HSCT donor had already been identified for all children. It is possible that caregivers of children who had to wait longer to find a donor experienced increased psychological distress during the time waiting for a donor, but that was not assessed in this study.

In terms of the fourth aim, racial/ethnic group differences were mostly accounted for by socio-demographic factors. The differences between Hispanic/Latino and non-Hispanic Black caregivers on the BDI and IES were no longer statistically significant after controlling for socio-demographic factors. This finding is consistent with research suggesting that socioeconomic differences often account for observed differences between racial/ethnic groups [28]. There was evidence that differences between Hispanic/Latino and non-Hispanic White caregivers on the BDI remained significant after accounting for socioeconomic factors. This finding is contrary to national survey data suggesting that Hispanic individuals report lower rates of psychological distress and psychiatric disorders compared with non-Hispanic Blacks and Whites [19]. However, it is consistent with evidence that Hispanic caregivers of medically-ill family members report greater depression symptoms than Caucasian caregivers [41]. In broader caregiver literature, it has been suggested that ethnic differences in psychological distress may be related to appraisals of the caregiver experience [42]. For example, a study of spousal caregivers found that African-American caregivers made more positive appraisals of the situation, which contributed to lower levels of depression [41]. Another possible explanation is the degree of acculturation played a role.

One indicator of acculturation is primary language. To explore this possibility, we compared Hispanic/Latino caregivers who completed the study in Spanish to those who completed in English, and found no significant differences in psychological distress. Although this finding suggests language may not account for the finding, future studies may consider additional measures of acculturation.

There are limitations that should be taken into consideration. First, the study was cross-sectional and does not examine psychological distress or diagnoses over time. Second, despite efforts to include a more diverse sample, we were not able to include many fathers and other primary caregivers (e.g., grandparents) or more diversity in terms of education. Third, we only assessed for three specific psychiatric diagnoses at the time of HSCT and did not include Adjustment Disorder, which was found to be prevalent in a prior study [11]. Since posttraumatic stress disorder (PTSD) requires symptoms be present for at least six months, we were not able to assess this diagnosis. Future studies may consider inclusion of additional SCID modules, specifically a clinical interview-based assessment of acute stress disorder (ASD) and Adjustment Disorder at the time of transplant. Fourth, while the term 'Hispanic/Latino' is frequently used in research, it can be problematic due to differences between subgroups such as Mexican-American, Puerto Rican, and Central American [20]. Future studies may consider examining specific subgroups. Additionally, the majority of Hispanic/Latino caregivers in our sample were from one study site and may reflect psychological distress specific to this site, which may limit generalizability to other Hispanic/Latino caregivers. Finally, the sample consisted of caregivers who agreed to participate in a randomized clinical trial. It is possible that caregivers who declined participation may report more depressive symptoms, anxiety symptoms, posttraumatic stress symptoms, or met criteria for a SCID diagnosis, which may impact the reported prevalence rates. Comparisons could not be made between participants and refusers on distress, as these data were not collected.

Despite the limitations, the current study offers valuable information about the prevalence of depressive symptoms, anxiety symptoms, posttraumatic stress systems, and SCID diagnoses among caregivers of children preparing to undergo HSCT, as well as factors associated with the symptoms and receiving a diagnosis. There are several clinical implications and areas of future research that can be gleaned from the findings. The assessment of posttraumatic stress symptoms is important, as it may be more prevalent than global depressive symptoms or anxiety symptoms. Utilizing global indicators may underestimate the prevalence of distress in this population. Since a history of psychological/psychiatric care may be a risk factor for depressive symptoms, posttraumatic stress symptoms, and psychiatric diagnosis during HSCT, professionals working with this population should take this into consideration. Other factors, such as being married and having a child undergoing allogeneic transplant, may also place caregivers at increased risk. However, further research is needed to understand these findings, particularly relationship factors which may make a married caregiver vulnerable to psychological distress. The limited demographic and medical factors associated with the psychological distress measures and receiving a SCID diagnosis highlight the importance of assessing all caregivers during this time rather than those who are traditionally at greater psychosocial risk (e.g., single parents). Most racial/ethnic differences in distress were accounted for by socio-demographic factors. There was evidence Hispanic/Latino caregivers

may be at greater psychological risk than non-Hispanic White caregivers. However, further research is needed to better understand the reasons for this finding. More research is needed to examine the trajectories of psychological distress and psychiatric diagnoses over the course of the HSCT. Longitudinal research will help identify factors which may play a role in psychological adaptation to the HSCT experience. Given the relatively high prevalence of posttraumatic stress symptoms and SCID diagnoses in the sample, it may be beneficial to develop and test effective psychosocial interventions to deliver to caregivers during the time preceding HSCT. The larger study is in the process of evaluating a brief intervention delivered in the time immediately following HSCT.

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Highlights

- More than half of primary caregivers report clinically-significant posttraumatic stress symptoms.
- Primary caregivers report mild anxiety and depressive symptoms during child HSCT.
- Twenty-seven percent of caregivers met criteria for a psychiatric diagnosis.
- Prior psychological/psychiatric care is a risk factor for psychological distress.
- Socio-demographic factors account for most racial group differences in distress.

Table 1

Demographic and Medical Characteristics

Variable	N	(%)	M	(SD)	Range
Caregiver Age [years]			37.43	(8.1)	18–62
Relationship to Patient					
Mother	189	(88)			
Father	18	(8)			
Other	8	(4)			
Marital Status					
Married	148	(69)			
Not married	67	(31)			
Household income [\$]					
0–\$19,999	40	(19)			
\$20,000–49,000	72	(35)			
\$50,000–79,000	34	(16)			
Above \$80,000	60	(29)			
Caregiver Race					
Non-Hispanic White	103	(48)			
Non-Hispanic Black	57	(26)			
Hispanic/Latino	30	(14)			
Other	25	(12)			
Caregiver Education					
< High school	16	(7)			
High school degree/GED	39	(18)			
Some college	79	(36)			
College/graduate school	81	(38)			
Number of Additional Children					
0	34	(16)			
1 or 2	139	(65)			
3 or 4	32	(14)			
5 or more	10	(5)			

Variable	N	(%)	M	(SD)	Range
Child Age [years]			8.54	(5.2)	<1–19
Child Gender					
Male	121	(56)			
Female	94	(44)			
Child Diagnosis					
Cancer	109	(51)			
Non-cancer	106	(49)			
Time to Find Donor [months]			2.98	(11.6)	0–120
Type of Transplant					
Allogeneic	173	(80)			
Autologous	42	(20)			
Caregiver History Psychiatric Care					
Yes	120	(56)			
No	95	(44)			
Caregiver Use of Psychosocial Resources in the Past Month					
Yes	123	(57)			
No	92	(43)			

Table II

Psychological Distress and SCID Diagnoses

Measure	<i>M</i>	(<i>SD</i>)	<i>N</i>	(%)
Beck Depression Inventory	11.7	(7.8)		
Minimal (0–9)			90	(42)
Mild (10–18)			90	(42)
Moderate (19–29)			29	(14)
Severe (29–63)			5	(2)
Beck Anxiety Inventory	11.5	(9.8)		
Minimal (0–9)			113	(53)
Mild (10–18)			55	(26)
Moderate (19–29)			32	(15)
Severe (29–63)			14	(6)
Impact of Event Scale	31.3	(22.5)		
Below clinical cut-off (< 26)			96	(45)
Clinical cut-off (>26)			116	(54)
SCID Diagnoses				
Major Depression (MD)			38	(18)
Generalized Anxiety Disorder (GAD)			33	(15)
Panic Disorder (PD)			7	(3)
At Least One SCID Diagnosis				
Yes			58	(27)
No			157	(73)

Table III**Regression Analyses for Psychological Distress and Diagnosis**

Predictors	BDI β	BAI β	IES β	SCID χ^2
Demographic variables				
Caregiver age	.02	-.02	.05	0.58
Mother (yes/no)	.01	.06	-.04	0.13
Married (yes/no)	.08	.12	.17*	1.50
Education	.003	-.08	.01	0.28
Income	-.10	-.12	.06	2.45
Child gender	-.04	.04	.04	2.53
Total additional children	.07	.11	.04	.002
Medical variables				
Months to find donor	.06	-.03	-.03	0.31
Type of HSCT (auto vs allo)	-.04	.05	.18*	0.001
Child diagnosis (cancer vs non)	.07	.009	-.12	0.06
Psychological				
History of psychiatric treatment	.15	.22**	.03	7.43**
Current use of psychosocial	.19*	.05	.12	3.18

Note.

*
 $p < .05$,

**
 $p < .01$

Table IV

Racial/Ethnic comparisons on the BDI, BAI, and IES

Measure	<i>M</i>	<i>F</i>	<i>p</i>
Beck Depression Inventory		3.04	.05
Non-Hispanic White	11.64		
Non-Hispanic Black	10.81		
Hispanic/Latino	15.11		
Beck Anxiety Inventory		2.23	.106
Non-Hispanic White	11.64		
Non-Hispanic Black	10.16		
Hispanic/Latino	14.92		
Impact of Events Scale		3.03	.05
Non-Hispanic White	30.64		
Non-Hispanic Black	27.17		
Hispanic/Latino	39.76		