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## The Role of Social and Cognitive Processes in the Relationship between Fear Network and Psychological Distress among Parents of Children Undergoing Hematopoietic Stem Cell Transplantation

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### Abstract

The current study examined whether cognitive and social processing variables mediated the relationship between fear network and depression among parents of children undergoing hematopoietic stem cell transplant (HSCT). Parents whose children were initiating HSCT ( $N = 179$ ) completed survey measures including fear network, Beck Depression Inventory (BDI), cognitive processing variables (positive reappraisal and self-blame) and social processing variables (emotional support and holding back from sharing concerns). Fear network was positively correlated with depression ( $p < .001$ ). Self-blame and holding back emerged as individual partial mediators in the relationship between fear network and depression. Together they accounted for 34.3% of the variance in the relationship between fear network and depression. Positive reappraisal and emotional support did not have significant mediating effects. Social and cognitive processes, specifically self-blame and holding back from sharing concerns, play a negative role in parents' psychological adaptation to fears surrounding a child's HSCT.

### Keywords

pediatric hematopoietic stem cell transplant; fear; psychological adaptation; parents

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Conflict of Interest. First author, second author, third author, fourth author, fifth author, and sixth author declare that they have no conflict of interest.

Informed Consent. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation of (name of participating institutions) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained for all participants for being included in this study.

Hematopoietic stem cell transplantation (HSCT) is a medical procedure that can be used in the treatment of oncologic diseases, such as leukemia, and hematologic diseases, such as sickle cell anemia. Hematopoietic stem cells are blood cells that can give rise to other cells through self-renewal and differentiation. They are utilized in the transplantation process to replace malignant cells and give rise to healthy cells. The cells are harvested prior to transplant from either the patient (autologous transplant) or from a donor (allogeneic transplant) through a process by which blood is taken from the donor and the hematopoietic stem cells are extracted. These cells can be frozen and stored for prolonged periods of time until the patient is ready for the transplant. Prior to HSCT, a child is hospitalized and must undergo various treatment procedures including chemotherapy and/or radiation to destroy malignant cells. During HSCT, hematopoietic stem cells are transfused into the child's bloodstream to replace the destroyed cells. While HSCT can provide life-saving treatment to children, the process is physically demanding due to preparatory regimens of chemotherapy and/or radiation, prolonged hospital stays, risk of infection following the transplant, and graft versus host disease (Cohen, Ley, & Tarzian, 2001; Maltezou et al., 2000). There are long-term medical complications and quality of life issues, including fatigue, fertility concerns, risk of secondary malignancies, cognitive difficulties, and potential disease recurrence (Baker et al., 2003; Fisher, 1999; Mosher, Redd, Rini, Burkhalter, & DuHamel, 2009; Titman et al., 2008). Having a child undergo HSCT can be distressing. Indeed, research suggests that parents experience symptoms of anxiety, depression, and posttraumatic stress (Dermatis & Lesko, 1990; Greening & Stoppelbein, 2007; Manne et al., 2003; Nelson, Gleaves, & Nuss, 2003; Phipps, Dunavant, Lensing, & Rai, 2004), and that 12% meet diagnostic criteria for posttraumatic stress disorder (PTSD; Manne et al., 2004). The highest levels of distress are reported during the time preceding and immediately following the transplant (Phipps, Dunavant, Lensing, & Rai, 2005). Factors linked to increased distress include younger age (Manne et al., 2004), lower income (Manne, 2001), greater transplant risk (Manne et al., 2003), and greater family conflict (Phipps & Mulhern, 1995).

An important factor to consider in parents' psychological adjustment to a child's HSCT is the fear network. Creamer and colleague (1992) proposed that a difficult life event results in the formation of a fear network, which consists of cognitive, affective, and physiological responses to that event. During a difficult life event, such as a child's HSCT, the individual develops beliefs about the threat the event poses to the child's life and the potential for suffering. The individual also experiences emotional and physiological fear reactions surrounding the event. The beliefs and experience of fear form during the time surrounding the difficult experience and comprise the fear network (Creamer, Burgess, & Pattison, 1992). The components of the fear network have been associated with PTSD symptoms among individuals exposed to trauma (Creamer et al., 1992) and parents of pediatric cancer survivors (Kazak, 1998). A fear network measure was previously developed specifically for parents whose child was undergoing HSCT (Manne et al., 2002). In prior studies using this measure, the fear network was linked to parent psychological distress at the time of child's transplant (Manne et al., 2002; DuHamel et al., 2004) and up to six months after the transplant (DuHamel et al., 2007), suggesting that it is an important component in parents' psychological adaptation to a child's HSCT.

Despite research linking fear network and psychological distress among parents of children undergoing HSCT, little is known about mechanisms through which the fear network may impact psychological distress. Fear network is based on social-cognitive processing theory which suggests that fears are processed on a cognitive and social level. Cognitive processing includes various strategies that involve confronting, contemplating, and re-evaluating the event in order to assimilate it into existing views or to change existing views to accommodate it. Social processing involves sharing thoughts and feelings within a social context in order to facilitate the cognitive processing (Lepore, 2001). Therefore, the fear network may impact psychological adaptation through specific cognitive and social mechanisms.

Prior research has supported the role of social and cognitive processes in parents' psychological adaptation to a child's transplant, specifically that fear appraisals surrounding the transplant and unsupportive responses from family and friends were related to PTSD symptoms after the transplant (Manne et al., 2002). However, the prior study did not examine the mechanisms by which fear network impacts psychological distress. There has been one study that examined a cognitive processing model of fear network and psychological distress among mothers of children undergoing HSCT (DuHamel et al., 2004). The study found that cognitive intrusions partially mediated the relationship between fear network and psychological distress. However, the authors noted limitations in the study. First, the study included only cognitive intrusions and avoidance as potential mechanisms in the relationship between fear network and psychological distress. There are additional cognitive processes which may serve as mechanisms. Second, the study did not assess the role of social processing, which is believed to be a component of psychological adaptation to difficult life experiences (Lepore, 2001). Further research is needed to identify additional cognitive and social processing variables that explain the relationship between fear network and psychological distress.

The purpose of the current study was to utilize social-cognitive processing theory to explore the relationship between fear network and psychological distress. We focused on depression as an indicator of psychological distress due to past research recognizing depression symptoms in this population (Dermatis & Lesko, 1990; Manne et al., 2003; Nelson, Gleaves, & Nuss, 2003; Phipps, Dunavant, Lensing, & Rai, 2004), as well as research linking the fear network to symptoms of depression (DuHamel et al., 2004). We proposed four novel cognitive and social processing variables as potential mediators: 1) Positive reappraisal, which is an adaptive cognitive process; 2) Self-blame, which is a maladaptive cognitive process; 3) Emotional support, which is an adaptive social process; and 4) Holding back from sharing concerns with friends and family, which is a maladaptive social process. Positive reappraisal refers to cognitive efforts to assimilate a difficult life experience into existing views by creating beliefs about positive meaning (Carver, Scheier, & Weintraub, 1989; Lepore, 2001). Self-blame is a cognitive process by which an individual attempts to make sense of an experience and incorporate it into existing views through beliefs about one's role in the cause and impact of the experience (Carver et al., 1989; Carver, 1997; Lepore, 2001). Emotional support refers to the degree to which friends and family respond to the child's HSCT in a manner that facilitates adaptive social processing. Supportive social interactions make positive thoughts and emotions more accessible, thus

reducing the negative impact of a difficult life event (Lepore, 2001). Finally, holding back from sharing HSCT concerns with family and friends hinders the opportunity for social processing of the experience and limits opportunities to find meaning, re-evaluate, and process fears related to the experience (Lepore, 2001; Porter, Keefe, Hurwitz, & Faber 2005; Porter, Keefe, Wellington, & de Williams 2008).

While there are many cognitive and social processes that could be examined using this framework, we chose to focus on these four variables for four reasons. First, previous research has linked these cognitive and social processes to psychological adaptation in this population and among parents of children diagnosed with chronic illness (Greening & Steppelbein, 2007; Manne et al., 2003; Nelson, Miles, & Belyea, 1997; Rini et al., 2008). Second, these cognitive and social variables have been linked to fear in broader health populations (Llewellyn, Weinman, McGurk, & Humphris, 2008; Myers et al., 2013; Santavirta, Kettunen, & Solovieva, 2001). Third, these variables are consistent with a social-cognitive processing theory of psychological adaptation to illness (Lepore, 2001), which emphasizes that psychological adaptation is impacted by cognitive efforts to create positive meaning (positive reappraisal) and reduce negative beliefs about oneself (self-blame) and social efforts to share feelings about the difficult experience within a supportive context (emotional support) rather than not sharing (holding back). Finally, we recognized that existing psychotherapeutic interventions target these processes and understanding the roles of these processes within this population may help identify potential intervention targets to facilitate psychological adaptation.

Based on social-cognitive processing theory we proposed a model of fear network and psychological distress. We predicted that greater fear, as measured by the fear network, would be related to greater depression and that this relationship would be mediated by positive reappraisal, self-blame, emotional support, and holding back. We predicted that parents with greater fear would be less likely to engage in positive reappraisal, more likely to engage in self-blame, less likely to report supportive behaviors from friends and family, and more likely to hold back from sharing concerns with friends and family, and that these processes would serve as mechanisms in the relationship between fear network and depression. The proposed model is presented in Figure 1.

## Methods

### Participants

The cross-sectional study utilized baseline data from an ongoing randomized clinical trial evaluating the efficacy of a psychological intervention versus usual care among parents whose child is undergoing HSCT (Manne, unpublished). The sample included 179 primary caregivers of children scheduled to undergo HSCT at four different hospitals in the United States. Inclusion criteria for the randomized trial were: 1) biological or foster parent of a child under 18 years scheduled for HSCT within a month; 2) child does not have a diagnosis of medulloblastoma or other cancer of the brain (due to timeline of clinical trial); 3) primary caregiver to the child scheduled for HSCT; 4) residential or cellular phone service (due to follow-up assessments for the clinical trial being administered via telephone); and 5) speaks, reads, and writes English or Spanish.

## Procedures

Eligible participants were identified by the research study assistant at the time of preparatory consultation for HSCT. At the time of this consultation, the decision for HSCT had been made and a donor had been identified. Eligible participants were approached about participation in the study and completed an informed consent document approved by the Institutional Review Board at each site. The parents completed a paper-and-pencil baseline questionnaire during the time preceding the HSCT. The data utilized in the current study was obtained from the baseline questionnaire. Spanish translation for all study materials was accomplished by using a double translation approach, which involves one translator translating the materials from English to Spanish and second translator translating the Spanish translations back to English. Both versions in the original language were then examined for inconsistencies.

Of the 314 eligible parents approached for the clinical trial, 125 (40%) declined participation, 10 (3%) consented but withdrew before completing baseline questionnaires, and 179 (57%) consented to participate, completed baseline questionnaires, and are included in this study. The majority of refusers did not provide a reason for refusal. Among those that did provide a reason, lack of interest ( $n = 17$ ) and being too overwhelmed/stressed/tired ( $n = 8$ ) were most common. Comparisons between study refusers and participants on available data (age, race, child gender, child age) indicated that participation rates were significantly higher among individuals who identified as Hispanic/Latino than individuals who identified as non-Hispanic/Latino (76.5% and 56%, respectively). The participation rates were lower at two sites (46.7% and 47.1%) when compared to two other sites (64% and 70.4%).

## Measures

**Demographics**—Demographic data was obtained on the baseline survey, including age, gender, race, marital status, education level, income, and child age and gender.

**Medical chart**—Medical chart review captured medical data including child diagnosis, time since diagnosis, type of transplant (autologous vs. allogeneic), whether this was the child's first transplant, and time to find a donor.

An estimate of transplant risk was calculated by the researchers, including an expert in the field, utilizing the medical data obtained for the purpose of the study. Four medical factors were taken into consideration: 1) whether it was the child's first transplant; 2) child's diagnosis (blood-related cancers, non-blood cancers, or non-cancer); 3) whether the chemotherapy administered was the child's first; and 4) type of transplant (autologous, allogeneic-peripheral/marrow, or allogeneic-cord). These factors were identified by the expert as factors that may influence the degree of risk of transplant. Each factor was rated for degree of risk based on expert opinion. Estimated risk was computed by summing the ratings for each item for a total ranging from 0–6, with higher scores indicating greater estimated risk to transplant.

**Depression**—The Beck Depression Inventory-II (BDI) (Beck, Steer, & Brown, 1996) is a widely accepted scale used to assess symptoms of depression. The scale consists of 21 items

that assess the emotional, cognitive, and somatic components of depression. Parents rated symptoms of depression over the past week. The measure has demonstrated strong psychometric properties and internal consistency in prior work with this population (Manne et al., 2003). Internal consistency in the present study was .86.

**Fear Network**—The Fear Network measure was previously developed to assess fears related to the child’s HSCT (Manne et al., 2002). The measure assesses three components of fear, including threat to life, potential for suffering, and magnitude of fear as each relates to the child’s HSCT. Threat to life was assessed by one item, “How scared are you that your child’s treatment will not be successful?” to which participants responded on a 9-point scale ranging from 0 = not at all to 8 = extremely. Potential for suffering was assessed by three items: 1) “How scared are you that you’ll never be able to put the experience behind you?” to which participants responded on a 9-point scale ranging from 0 = not at all to 8 = extremely; 2) “Overall, how well would you say your child has adjusted to the demands of his/her treatment?”, referring to treatment completed prior to HSCT, i.e., chemotherapy and/or radiation, and to which participants responded on a 5-point scale ranging from 1 = not at all well to 5 = extremely well, and which was reverse coded; and 3) “How distressed is your child about his/her illness?” to which participants responded on a 4-point scale ranging from 1 = extremely to 4 = not at all distressed, and which was reverse coded. Magnitude of Fear was calculated by combining responses to two items that tapped parents’ fear, with one item that utilized a 7-point Likert scale to assess frequency of fears, and a second item that used an 11-point Likert scale to assess intensity of fears. The composite measure is calculated based on the six items. Since the components utilize different scale ranges, scores on each component are standardized and a standardized composite fear appraisal score is calculated. Higher scores indicate greater fear appraisals. The measure has been previously utilized in this population and has demonstrated acceptable reliability (DuHamel et al., 2007; DuHamel, et al., 2004). Internal consistency was .79.

**Positive reappraisal**—The 4-item positive reappraisal subscale of the COPE was utilized (Carver, et al., 1989). Parents rated on a 4-point scale the degree to which they relied upon positive reappraisal to cope with their child’s HSCT. Sample items include “I’ve been trying to see it in a different light, to make it seem more positive” and “I’ve been trying to learn something from the experience.” This subscale has been utilized in prior work with this population (Manne et al. 2003). Scores ranged from 4–16 with higher scores indicating greater use of positive reappraisal. Internal consistency was .76.

**Self-blame**—The 2-item self-blame subscale of the COPE was utilized (Carver et al., 1989). Parents rated on a 4-point scale the degree of self-blame related to the HSCT experience. Sample items included “I’ve been blaming myself for things that happened” and “I’ve been criticizing myself.” Scores ranged from 2–8 with higher scores indicating greater self-blame. The self-blame subscale has demonstrated adequate psychometric properties in prior work with parents of children diagnosed with chronic illness (Wong & heriot, 2008). Internal consistency was .71.

**Emotional support**—An adapted version of the 13-item emotional support subscale (referred to as nondirective support in Barrera & Ainlay, 1983) of the Inventory of Socially Supportive Behaviors (Barrera, Sandler, & Ramsay, 1981) was utilized to assess family and friends responses specific to the child’s HSCT. Parents rated on a 4-point scale the degree to which their friends and family responded in certain ways during the past week (1 = never responded this way; 4 = often responded this way). Sample items include “Says things that make your situation clearer and easier to understand” and “Helps you to understand your feelings.” Factor analysis of the scale has demonstrated the clinical utility of the separate scales, including emotional support (Finch, Barrera, Okun, Bryant, Pool, & Snow-Turek, 1997). Scores ranged from 13–52 with high scores indicating greater emotional support. Internal consistency was .91.

**Holding back**—A scale adapted from Pistrang and Barker (1995) and used by Porter et al. (2005) was used to assess the degree to which parents hold back from sharing concerns with family and friends over the past week. Parents rated the degree to which they held back from sharing nine specific concerns related to the child’s transplant (e.g., child’s physical symptoms, relationship with child) on a 6-point scale (0 = *not at all* to 5 = *a lot*). Sample items include “How much do you hold back from talking to family and friends about concerns about your child’s psychological well-being?” and “How much do you hold back from talking to family and friends about concerns about your child’s physical symptoms (e.g., pain)?” The holding back scale has been utilized in various health populations and has demonstrated adequate reliability (Manne et al., 2010; Porter et al., 2005). Scores ranged from 0–45 with greater scores indicating a greater tendency to hold back. Internal consistency was .89.

### Statistical Analysis Plan

Data were analyzed utilizing Statistical Packages for Social Sciences (SPSS) and SAS. Correlational analyses were conducted to determine demographic and medical variables related to fear network and/or depression. Only variables significantly ( $p < .05$ ) related to either fear network or depression were included in the model as covariates.

To address the primary aim, mediation analyses were conducted to examine the total, direct, and indirect effects of the fear network on depression. Transformations were considered for variables that did not satisfy assumptions for traditional linear models to reduce influence of outliers. First, we examined the degree to which each proposed mediator alone accounted for the relationship between fear network and depression. . Second, we utilized a multiple mediator model (Preacher & Hayes, 2008) to examine the extent to which the proposed mediators as a set accounted for the fear network and depression relationship. The cognitive and social processing variables, positive reappraisal, self-blame, emotional support, and holding back, were considered in individual mediation models. Those that were significant individually were included simultaneously in a multiple mediator model. The analyses examined the direct effect, which assesses the relationship between fear network and depression, the overall indirect effect, which assesses the impact of the mediators as a set, and the unique (i.e., partial) indirect effects for each mediator, which assesses the impact of each mediator individually. The SAS macro “PROCESS” (downloaded from



[www.afhayes.com](http://www.afhayes.com) on February 4, 2013; see Hayes, 2013) was used for the multiple mediator models. To estimate the mediational effects with 95% confidence intervals, bootstrapping, as described in Preacher and Hayes (2004), was used. This technique makes minimal assumptions about the distributions of the variables and empirically estimates the shape of the sampling distribution of the statistic, in this case the mediational effect which is the produce of two regression coefficients. In particular, 157 observations were sampled with replacement from the original data set of 157 observations 1,000 times to create 'bootstrap samples.' For each bootstrap sample, the mediation effect is estimated. The mediation effect for the study is estimated as the mean of the bootstrapped mediation effects and 95% confidence intervals are obtained by selecting the 2.5<sup>th</sup> percentile and the 97.5<sup>th</sup> percentile of the sampling distribution of these effects. This procedure is done to gain a better sense of the variability within the data and provide a better estimate of the study variables. Sensitivity analyses re-examined these direct and indirect effects of fear network after adjusting for parent age due to evidence in prior studies with this population that younger parents report greater psychological distress (Barrera Atenafu, Doyle, Berlin-Romalis, & Hancock, 2012; Manne et al., 2004; Phipps et al., 2005).

Initial scatterplots of depression versus fear network and the mediators as well as fear network versus the mediators demonstrated that depression and self-blame were positively skewed with heterogeneous variances while emotional support and positive reappraisal were strongly, negatively skewed. A square root transformation improved the distribution for depression which created homogeneous variances and resulted in scatter plots that were more appropriately modeled with standard linear models. Squared transformations of emotional support and positive reappraisal created more symmetric distributions, reducing the influence of outliers on the regression lines. These transformations were used in all formal analyses.

There were two participants with one missing item on the BDI and two participants with one missing item on the emotional support scale. Mean substitution was utilized for these four participants to correct for the missing item and calculate a scale total. There were 22 participants that did not complete at least one of the six study measures. Eight participants did not complete the fear network scale, one participant did not complete the self-blame scale, three participants did not complete the positive reappraisal scale, one participant did not complete the emotional support scale, and eleven participants did not complete the holding back scale. The 22 incomplete cases were included in descriptive analyses, but only complete cases were used in the multivariate analyses ( $n=157$ ). Comparisons between complete and incomplete cases revealed no significant differences on demographic, medical, or study variables, except that a greater percentage of complete cases were married (73%) compared with incomplete cases (43%) ( $p = .006$ ).

## Results

### Demographic and Medical Data

The majority participants were mothers of the child undergoing HSCT (87.7%), married (68.7%), Caucasian (50.3%), and had completed at least some college (74.8%). The mean age was 37.1 years ( $SD = 8.3$ ). The majority of the children undergoing HSCT were male

(58.1%) and the mean age was 8.5 years ( $SD = 5.3$ ). For most children, this was their first transplant (84.9%) and the most common type was allogeneic (80%). On average, a donor was located within 2.8 months ( $SD = 12.2$ ). Detailed demographic and medical data is presented in Table 1.

### Correlation Analyses

Correlational analyses revealed that none of the parent demographic (age, race/ethnicity, marital status, education level, income), child demographic (age and gender), or medical variables (time since diagnosis, relationship to donor, time to find donor, type of transplant, transplant risk) significantly correlated with fear network or depression. Due to the small number of fathers in the study ( $n = 6$ ), it was not possible to examine the impact of gender on fear network and depression. Depression significantly correlated with fear network ( $r = .55, p < .0001$ ) self-blame ( $r = .49, p < .0001$ ), emotional support ( $r = -.21, p = .0093$ ), and holding back ( $r = .47, p < .0001$ ). Depression had negligible correlation with positive reappraisal ( $r = .00, p = .97$ ). The fear network, when considered individually, accounted for 30.4% of the variation in depression. The fear network was also significantly correlated with self-blame ( $r = .35, p < .0001$ ) and holding back ( $r = .35, p < .0001$ ), but not with positive reappraisal or emotional support. See Table 2 for correlational analyses.

### Mediation Models

**Single mediation models**—The four single mediation models included positive reappraisal, self-blame, emotional support, and holding back as mediators in separate models. Self-blame was a significant mediator in the relationship between fear network and depression ( $b = 0.055, 95\% \text{ CI: } 0.025, 0.092$ ). Note that zero, which would indicate no mediational effect, is not included in the interval, indicating a significant effect. This indirect effect accounted for 27.1% (95% CI: 12.0%, 53.0%) of the total effect of fear network on depression. Holding back was also a significant mediator ( $b = 0.050, 95\% \text{ CI: } 0.024, 0.087$ ), accounting for 23.7% (95% CI: 10.6%, 49.2%) of the total effect of fear network on depression. Neither positive reappraisal nor emotional support significantly mediated the association between fear network and depression ( $b = -0.003, 95\% \text{ CI: } -0.020, 0.003$  and  $b = 0.007, 95\% \text{ CI: } -0.003, 0.027$ , respectively). Therefore, they were not included in the multiple mediator analysis.

**Multiple mediation model**—The multiple mediator model yielded similar information. Overall, 34.3% (95% CI: 19.8%, 53.1%) of the association between fear network and depression could be explained by self-blame and holding back. Self-blame ( $b = .047, 95\% \text{ CI: } 0.021, 0.083$ ) and holding back ( $b = 0.041, 95\% \text{ CI: } 0.019, 0.075$ ) had significant indirect effects in the model. Self-blame accounted for 18.2% (95% CI: 8.7%, 30.6%) of the indirect effect of fear network on depression. Holding back accounted for 16.1% (95% CI: 7.1%, 29.0%) of the indirect effect of fear network on depression.

### Discussion

The study provided support for a social-cognitive processing mediation model of the association between fear network and depression among parents of children undergoing

HSCT, suggesting that the impact of parents' fears on depressive symptoms may be influenced by the way that the parent processes those fears and the experience on a cognitive and social level. Prior studies have noted that fear network and cognitive and social processes play a role in psychological distress over time in this population (Manne et al., 2002). Subsequent research suggested that cognitive processes, specifically cognitive intrusions, served as a mechanism in the relationship between fear network and parent distress (DuHamel et al., 2004). This study expanded those findings to identify additional cognitive and social processes as mechanisms in the relationship between fear network and depressive symptoms.

As predicted, fear network was positively correlated with parents' level of depression and this relationship was partially mediated by cognitive and social processes, specifically self-blame and holding back from sharing concern related to the HSCT. Together, self-blame and holding back accounted for over a third of the association in the multiple mediator model. From a social-cognitive perspective, self-blame may be utilized to make sense of the experience through beliefs about one's role in the cause and impact of the experience. Self-blame is generally regarded as a maladaptive cognitive process as it tends to be related to worse psychological recovery from the difficult life events (Frazier & Schauben, 1994). Indeed, among parents of children undergoing bone marrow transplant, self-blame has been linked to psychological distress (Kronenberg et al., 1998). In the current study, fear network was positively correlated with self-blame, suggesting that as parents experience greater fears surrounding the HSCT experience, they may attempt to incorporate those fears into their views through beliefs about their responsibility and blame in the child having to undergo HSCT. Parents may choose to engage in self-blame as a way of finding meaning for the experience, rather than blaming others. It may be important for professionals to assist parents to challenge any beliefs about self-blame and develop more adaptive beliefs about the experience in order to facilitate psychological adaptation. Self-blame is a complex construct with different types, including characterological blame, which focuses on one's character as the source of the transgression, and behavioral blame, which focuses on a specific behavior and holds more promise for rectifying or challenging those beliefs (Janoff-Bulman, 1979; Lutwak, Panish, & Ferrari, 2003). While the current study did not differentiate the type of self-blame, future research may consider examining whether characterological self-blame has a greater negative impact than behavioral self-blame.

Holding back represents a social process by which individuals refrain from sharing their concerns with family and friends, which limits opportunities to process and integrate concerns into existing views. Holding back has emerged as a predictor of psychological distress in numerous medical populations (Porter et al., 2005; Porter et al., 2008). Additionally, parents of children undergoing HSCT who avoid expressing concerns tend to be more distressed (Phipps et al., 2005). This current study provided further evidence that holding back may be related to psychological distress among parents of children undergoing HSCT, particularly in regard to the relationship between parents' fears surrounding the HSCT and symptoms of depression. Research suggests that talking about concerns and feelings with a supportive person can help people cope with stressful situations (Cohen & Wills, 1985) and process thoughts and feelings about the situation in order to think about it in a more adaptive manner (Lepore, 2001). Research has indicated that individuals will often

not disclose concerns to protect others (Manne, 1998), but that this protective buffering is not necessarily adaptive (Dunkel-Schetter, 1984; Manne, Dougherty, Veach, & Kless, 1999). As parents' fears increase they may tend to refrain from sharing concerns with their support network in order to protect their family and friends, but this may limit opportunities for adaptive processing of the experience. It may be important for professionals to assist parents in sharing their fears and concerns in a supportive context.

There was no evidence that positive reappraisal or emotional support had indirect effects in the relationship between fear network and depression. It is interesting that the maladaptive processes (i.e., self-blame and holding back) emerged as mediators, whereas the adaptive processes (i.e., positive reappraisal and emotional support) did not. A possible explanation is that maladaptive processes play a stronger role in the relationship between fear and depression, a negative measure of psychological outcome, while the adaptive processes may play a role in positive psychological adaptation. Indeed, there is evidence that adaptive coping and social support influence positive outcomes, such as emotional well-being in health populations (Zhou et al., 2010). It is also possible that positive reappraisal does not impact the relationship between fear network and depression initially, but that over time the ability to develop beliefs about meaning may facilitate psychological adaptation to fears surrounding the child's HSCT. Indeed, a study found that positive reappraisal at the time of transplantation was not related to mothers' depressive symptoms at the time of HSCT, but it was related to declines in depression over time (Manne et al., 2003). Emotional support was negatively correlated with depression, but not significantly related to the fear network, suggesting that a supportive social environment plays a role in psychological distress but not the degree of fear that a parent experiences in relation to the child's HSCT. A possible explanation is that as fears about the HSCT intensify, the parent's support network may remain intact, but the degree to which the parent chooses to share concerns and rely upon the friends and family for emotional support may change, meaning that parents perceive an emotional supportive system but hold back from relying upon support. In our findings, holding back was correlated with both emotional support and fear network. It is possible that parents who perceive an emotionally unsupportive environment hold back from sharing concerns and parents who experience greater fears also hold back, and that holding back is related to worse psychological adaptation. Further research is needed to examine the longitudinal role of these variables and whether they are associated with positive outcomes.

An interesting find was the significant positive correlation between holding back and emotional support, indicating that parents reporting more holding back reported greater emotional support. This is in contrast with research indicating that holding back is associated with lower levels of support and more unsupportive behaviors from family and friends (Figueiredo et al., 2004; Porter et al., 2005). A possible explanation is that family and friends may be sensitive to the parents' stress and when they notice a parent withdrawing or withholding, they may initially respond with greater efforts to provide emotional support. Longitudinal data is needed to determine whether the parents' holding back is in response to unsupportive behaviors from family and friends or if family and friends respond to holding back by initially offering emotional support and, over time, become less supportive. Another possible explanation is that the relationship between holding back and emotional support is not linear. High levels of holding back are associated

with unsupportive behaviors from family and friends (Figueiredo et al., 2004; Porter et al., 2005). However, low levels of holding back, where the parent shares too much, may also lead to a sense of burden among family and friends and they may respond by avoiding or not freely offering emotional support. Therefore, holding back may not be an entirely maladaptive strategy. It is possible that some level of holding back may be beneficial, as it may allow family and friends to provide optimal levels of support.

None of the demographic or medical variables were significantly related to fear network or depression. This finding is in contrast to prior studies linking lower psychological distress to higher income (Manne et al., 2003), Caucasian race (DuHamel et al., 2004), and lower transplant risk (Manne et al., 2003). However, other studies have found non-significant associations between demographic factors and parents' posttraumatic stress symptoms (Manne et al., 2002) and no link between transplant risk and depression (Manne et al., 2002) or fear network (DuHamel et al., 2004). There is also evidence that illness severity, caregiver or physician rated, is not related to parent distress in other pediatric illness populations (Canning, Harris, & Kelleher, 1996). The non-significant finding lends support for the importance of assessing all parents for psychological distress regardless of demographic or medical factors.

There are limitations to the current study that should be taken into consideration. First, the study was cross-sectional in design, which limits conclusions about direction of causality. It is possible that depression or fears influence social and cognitive processing. Additionally, the study focused on parents' fear network and processing at the time of the child's HSCT. Since parents' distress tends to decrease over time (Manne et al., 2002; Phipps et al., 2005), it is possible that the relationship between these variables changes. Longitudinal research is needed to determine the direction of these relationships over time. A second limitation is that we did not assess premorbid psychological distress among parents or children, which has been found to impact distress surrounding the transplantation (Phipps et al., 2005) and may play a role in the psychological adaptation to fears surrounding the HSCT. This may be an area of future study in order to better understand the impact of premorbid functioning. Third, the majority of participants were mothers, married, and relatively well-educated, which may limit the generalizability of the findings. Future studies should include more diverse samples, particularly more inclusion of fathers of children undergoing HSCT. However, it should be noted that the sample did include a relatively high percentage of minority parents. Fourth, the cognitive and social variables examined in this study are not all-inclusive and there are other factors that may play a role in the relationship between fear network and psychological distress. For example, acceptance of fears may facilitate psychological adaptation to fears. Future studies may consider additional variables. Fifth, the estimate of transplant risk was not assessed with a standardized measure and conclusions about the relationship between transplant risk and variables in this study should be interpreted with caution. Finally, it should be noted that parents in this study consisted of individuals who agreed to participate in a randomized clinical trial evaluating a therapy intervention and there may be certain factors that differentiate these parents from those who are not included in the study. Indeed, parents who identified as Hispanic/Latino were more likely to agree to participate in the study than parents who did not identify as Hispanic or Latino. Parents who agreed to participate in the intervention study may have more initial

fears surrounding the HSCT. Alternatively, parents who refused participation may have more fears surrounding HSCT. A common reason parents refused participation was feeling overwhelmed, suggesting this may be a possibility which may impact the results. However, comparisons could not be made between participants and refusers on these variables as these data were not collected.

Despite these limitations, there are many strengths of the study that should also be noted. The study is among the first to examine a model of fear network, cognitive and social processing variables, and depression among parents of children at the time of HSCT. The study expands upon existing research to better understand mechanisms by which parents' fears about a child's HSCT impact psychological distress utilizing a social-cognitive processing framework (Lepore, 2001). The significant findings warrant further research examining these factors in this population. The study included standardized measures and measures that have been previously utilized in this population, which can be utilized in future studies with this population. The identified mechanisms, namely holding back and self-blame, may be potential targets for interventions aimed at facilitating psychological adaptation, particularly interventions aimed at assisting parents to cope with fears surrounding the HSCT. Teaching parents to challenge beliefs about self-blame and to share their thoughts and feelings surrounding the HSCT in a supportive social context may be a way to enhance psychological adaptation to fears. Future research may also examine whether psychological interventions that target these processes impact parents' fear appraisals. Additionally, the findings may also provide insight into the role of the fear network in PTSD. Given research linking fear network to the development of PTSD over time in this population (Manne et al., 2002), further studies may apply this model to better understand how cognitive and social processing of fears surrounding HSCT may impact the development and course of PTSD.

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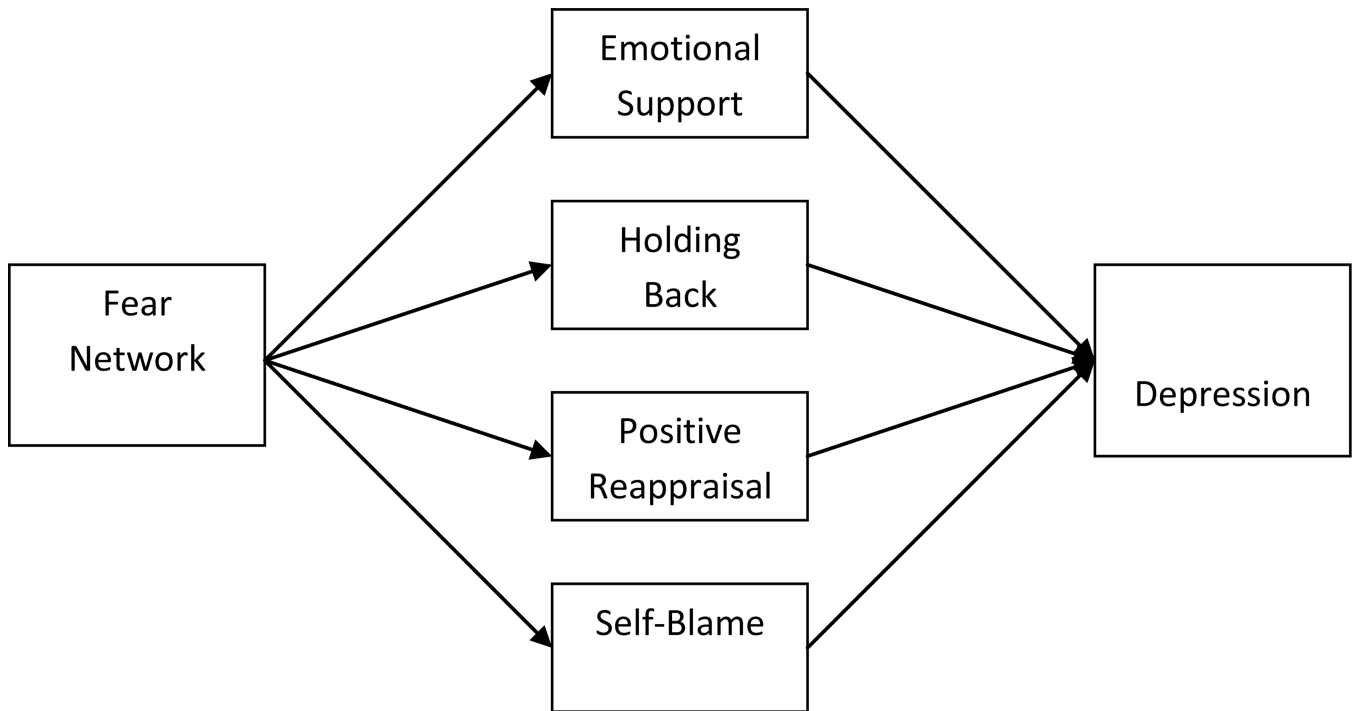
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**Figure 1.**

A social-cognitive model of fear network and psychological distress.

*Note.* The figure does not include correlations among the cognitive and social mediators

**Table 1**

Demographic and Medical Data for Study Participants [N=179]

Variable	N	%	M(SD)	Range
Parent Age [years]			37.11(8.28)	18–62
Household income [\$]				
0–\$19,999	33	19		
\$20,000–49,999	62	34		
\$50,000–79,999	27	15		
Above \$80,000	50	28		
Missing	7	4		
Relationship to Patient				
Mother	157	88		
Father	16	9		
Other	6	3		
Parent Race				
White/Caucasian	90	50		
African-American	48	27		
Hispanic/Latino	24	13		
Asian	6	3		
American Indian/Alaskan	2	1		
Unspecified	9	5		
Parent Education level				
< High school	13	7		
High school/GED	31	17		
Some college	42	23		
College graduate	57	32		
Graduate/Advanced degree	25	20		
Marital Status				
Married	123	69		
Never married	28	15		
Widowed	1	<1		
Divorced/Separated	26	14		
Child Age [years]			8.46(5.32)	<1–19
Child Gender				
Male	104	58		
Female	75	42		
Time since diagnosis [years]			2.26 (3.26)	<1–15
Time to find donor [months]			2.83(12.16)	<1–120
Type of Transplant	143	80		
Allogeneic	36	20		
Autologous				
Child's First Transplant	152	85		

Variable	<i>N</i>	%	<i>M(SD)</i>	Range
Yes	3	2		
No	24	13		
Missing				
Relationship to Donor	36	20		
Self	65	36		
Relative	78	44		
Unrelated				
Transplant Risk			3.71(0.7)	1–6

**Table 2**

Descriptive Statistics and Correlations for the Study Variables

Variable	1.	2.	3.	4.	5.	6.
1. Fear Network						
2. Depression (BDI)	.55***					
3. Positive Reappraisal	-.11	.003				
4. Self-Blame	.35***	.49***	.11			
5. Emotional Support	-.09	-.21**	.27**	-.04		
6. Holding Back	.33***	.47***	-.12*	.28**	.52***	
<i>M</i>		12.10	12.59	3.10	41.88	18.09
<i>SD</i>		7.97	3.02	1.54	8.44	12.41

\* Note.  $p < .05$ ,

\*\*  $p < .01$ ,

\*\*\*  $p < .001$

The mean and standard deviation for the Fear Network measure are not included because they are standardized scores with  $M = 0$  and  $SD = 1$ .