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Changing Factors associated with Parent Activation after Pediatric Hematopoietic Stem Cell Transplant

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Abstract

Purpose—To identify factors associated with parent activation in parents of children undergoing pediatric hematopoietic stem cell transplant (HSCT) in the 6 months following HSCT, and to address if their association with parent activation changes over time.

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DECLARATION OF CONFLICTING INTERESTS:

Dr. Judith Hibbard reports stock ownership and a consultancy role with Insignia Health, the entity responsible for the distribution and licensure of the PAM. The other authors declare no conflicts of interest with respect to research, authorship, and/or publication of this article. The authors have full control of all primary data and would give the journal permission to access the data upon request.

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Methods—Measures for this analysis, including the Parent Patient Activation Measure (Parent-PAM), were completed by parents (N=198) prior to their child's HSCT preparative regimen and again at 6 months post-HSCT. Clinical data were also collected. A repeated measures model was built to estimate the association between clinical and demographic factors and parent well-being on Parent-PAM scores. Interactions with time were considered to test for changing effects over time.

Results—Throughout the HSCT course, older parent age was associated with lower Parent-PAM scores ($\beta=-0.29$, $p=0.02$) and never being married was associated with higher scores (versus married, $\beta=12.27$, $p=0.03$). While higher parent emotional functioning scores were not associated with activation at baseline, they were important at 6 months (baseline: $\beta=-0.002$, $p=0.96$; interaction: $\beta=0.14$, $p=0.03$). At baseline longer duration of illness was associated with increased activation, but this effect diminished with time (baseline: $\beta=3.29$, $p=0.0002$; interaction: $\beta=-2.40$, $p=0.02$). Activation levels dropped for parents of children who went from private to public insurance (baseline: $\beta=2.95$, $p=0.53$; interaction: $\beta=-13.82$, $p=0.004$). Clinical events did not affect Parent-PAM scores.

Conclusions—Our findings reveal important changes in the factors associated with parent activation in the first 6 months after pediatric HSCT. These findings may reflect the emotional and financial toll of pediatric HSCT on parent activation.

Keywords

cancer; HSCT; children; patient activation; Parent-Patient Activation Measure

INTRODUCTION

Patient activation, defined as an individual's knowledge, confidence, and ability to manage their health or chronic illness [1], is thought to be essential to the delivery of effective care. The Chronic Care Model (CCM), developed by Wagner et al. and widely applied to the treatment of chronic illnesses, asserts that good clinical outcomes hinge on the exchange between an activated patient and a receptive, prepared clinical team [2]. Research in chronically-ill populations with diabetes [3], multiple sclerosis [4], cardiovascular conditions [5] and healthy adult populations [6,7] has shown associations between higher patient activation and better health status, health-related quality of life (HRQL), and adherence to healthy behaviors. In pediatrics, studies have highlighted the analogous importance of informed and self-efficacious parents in effectively caring for their children. Higher parenting self-efficacy (PSE), a related construct, in parents of children receiving standard outpatient care [8] or children with sickle cell disease [9], inflammatory bowel disease [10], or HIV [11] has been associated with better adherence to medications and improved clinical outcomes.

We recently reported on the novel construct of "parent activation" [12], which is defined as a parent's knowledge, confidence, and ability to manage *their child's* health or chronic illness and extends self-efficacy to self-management. Our analysis focused on parents of children who were scheduled to undergo pediatric hematopoietic stem cell transplant (HSCT). The relative influence of personal traits of the parent, the social environment

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surrounding the parent-child relationship, and characteristics of the child on parent activation were explored in a multivariable model. Our model revealed that higher parent activation at the time of HSCT was significantly associated with higher patient activation concerning the parent's own health, younger parent age, a longer duration of the child's illness, and worse rating of the parent's own general health. In contrast to other studies of the related constructs of patient activation and PSE, no significant associations were observed between parent activation and socioeconomic status, family characteristics, or the parent's emotional functioning [12].

Due to the novelty of our first analysis and the divergence between factors associated with parent activation and related constructs, we sought to evaluate parent activation longitudinally in our pediatric HSCT sample and to identify whether factors associated with parent activation change over the HSCT course. Moreover, as identified by Hibbard et al. (2007), while an abundance of studies evaluate the longitudinal effects of interventions on patient activation [13–15] or PSE [16,17], there is a dearth in the literature concerning the potential impact of other factors on changes in activation. Pediatric HSCT, an intensive, high-risk treatment regimen that often requires a prolonged hospitalization followed by a lengthy recovery, involves substantial fluctuations in daily life, financial resources, and the child's clinical status and, as such, creates an ideal scenario for an in-depth analysis of factors that influence parent activation longitudinally. We describe the results of an analysis of factors associated with parent activation in parents of children undergoing pediatric HSCT using a multivariable repeated measures model.

Based on the results of our previous analysis and those of previous studies of patient activation and PSE [12], we conjectured that the multi-faceted demands of the first six months post-HSCT would necessitate emotional and environmental resources, not essential at baseline, to achieve and/or maintain high parent activation. Therefore, we hypothesized several changes in factors associated with parent activation in our sample at baseline versus six months. We hypothesized that the effects of parent emotional function and social support, changing socioeconomic status, and duration of illness on parent activation would change over time. Additionally, we hypothesized that a difficult clinical course for the child would result in significantly lower parent activation over time, as evolving medical and treatment-related complications might challenge the parent's knowledge base and confidence in managing their child's health.

METHODS

Participants and Study Procedures

A comprehensive description of study recruitment can be found in our previous paper [12]. Briefly, 198 parent-child dyads from six HSCT centers nationwide were enrolled in the HSCT-Comprehensive Health Enhancement Support Study (CHESS™) [18,19], a randomized controlled trial of a web-based intervention designed to improve the health-related knowledge, skills, and quality of life of parents of children undergoing HSCT. The baseline evaluation was completed prior to the HSCT preparative regimen. Additional assessments were collected at 45 days, and 3, 6, 9, and 12 months post-transplant. By 6 months, 12 children had died and nine had withdrawn from the study. Further, 32 did not

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complete measures at the 6-month assessment (13 for medical reasons, 17 for non-medical reasons, and 2 for unknown reasons) and an additional six parents did not complete the primary outcome measure (the Parent-PAM). Therefore, a total of 139 dyads had available 6-month data.

Measures

Patient Activation Measure (PAM) and Parent PAM—The primary outcome of this study was parent activation concerning their child's health. Parent activation was assessed using the Parent-PAM, a modified version of the short form of the PAM [20], which is a well-validated measure of patient activation in chronically-ill [1,4,21,22] and healthy adult populations [6,15,22]. Both the PAM and Parent-PAM have shown acceptable internal consistency reliability ($\alpha = 0.86$ and $\alpha = 0.85$, respectively) in this population of parents of children undergoing HSCT [12]. The Parent-PAM modifies the items in the PAM to assess the parent's knowledge, confidence, and willingness to act in the context of managing their child's illness. Both measures consist of 13 items scored on a Likert scale with four different response options of varying agreement (from 1 = disagree strongly to 4 = agree strongly). All responses are summed and scaled from 0–100, based on a conversion chart provided by the developers of the measure [23]. This yields a total score where higher scores correspond to higher activation. Both PAM and Parent-PAM scores were collected at baseline and 6 months post-transplant.

Child Health Ratings Inventory –General Health: CHRIs-General—The CHRIs-General, a well-validated measure of HRQL [24,25] in both children undergoing pediatric HSCT and a parent, consists of 20 items, each utilizing a 5-point Likert scale. These items assess three domains of general functioning: physical, emotional, and role. A single item separately assesses general health. The scores are transformed to a 0–100 point scale, where higher scores indicate better functioning and health.

Two different sections of the parental CHRIs-General were completed, one about the parent's own HRQL and another about the child's HRQL. The CHRIs-General was collected at baseline, 45 days, and 3, 6, 9, and 12 months post-transplant. This analysis will use the following CHRIs-General scores collected at baseline and 6 months: the parent's rating of their emotional functioning, parent's rating of their general health, and parent's rating of their child's general health.

Medical Outcomes Study-Social Support Survey (MOS-SSS)—This 19-item validated and reliable questionnaire asks parents to rate their level of access to different types of functional support [26]. Parents responded on a 5-point Likert-type scale ranging from 1 (*none of the time*) to 5 (*all of the time*). A mean score for the overall support score was calculated (range, 1–5), where higher scores indicated more frequent availability of support. The baseline and 6-month social support score will be used in this analysis.

Demographic Variables—Prior to HSCT, demographic information was obtained from parents on the age, gender, and race/ethnicity of both dyad members. Parent participants also

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supplied information on insurance type, annual household income, job status, and marital status. Updates to insurance coverage were elicited from parent participants at 6 months.

Medical Assessment Variables—Baseline medical information was collected by trained study staff, using standardized medical chart review forms. Variables included causal diagnosis (malignant with or without prior relapse or non-malignant), duration of illness in months, and site of pre-HSCT care. Transplant-specific factors included type of HSCT (autologous, allogeneic related, allogeneic unrelated) and history of prior HSCT. Acute graft versus host disease (aGVHD) and transplant toxicity (as measured by the Bearman toxicity scale) [27] were collected at the end of hospitalization, 45 days, and 3 months. Chronic graft versus host disease (cGVHD) was collected at the end of hospitalization, 3, 6, and 12 months. Infection within the previous week was collected at all-time points, using the Common Toxicity Criteria of Adverse Events, v. 3.0 [28]. A dichotomous composite variable was created to indicate complications during the first 3 months post-HSCT (hereafter “early complications”). Early complications was defined as experiencing at least one of the following: aGVHD of grade 2 or higher or intermediate or poor toxicity (indicating intermediate or high levels of toxicity). A separate dichotomous variable was created to indicate the presence of limited or extensive cGVHD by 6 months [29,30]. Any systemic infection as defined as the presence of systemic infection by 6 months.

Data Analysis

Baseline demographic and clinical characteristics were described for the study population using means (standard deviations (SD)), medians (25^{th}–75^{th} percentile ranges), frequencies and percentages. Chi-squared and Fisher’s exact tests (binary or categorical variables) and two-sample t-tests (continuous variables) were used to determine if significant associations existed between baseline demographic or clinical variables and Parent-PAM completion status at 6 months.

Univariate analyses were conducted to assess hypothesized associations between Parent-PAM score and specific factors. We used maximum likelihood estimation with repeated measures (SAS Proc Mixed) to account for the correlations over time with an unstructured covariance matrix. Variables that were collected at multiple time periods were allowed to change over time within the model. For the duration of illness variable, the natural log transformation was used, as the data for duration of illness were not normally distributed. Time was an indicator variable for 6 months with baseline as the reference. We hypothesized that the relationship between the following variables and Parent-PAM score would change between baseline and 6 months: parental emotional functioning; duration of illness; early complications; cGVHD; any systemic infection, and drop in insurance (i.e., going from private to public insurance). These were tested with interaction terms between time and the covariate.

To assess which factors were associated with Parent-PAM scores over time, and to identify factors with changing effects on the score over time, a multivariable repeated measures model was constructed including univariate significant ($p<0.1$) covariates and interaction terms. Backwards elimination was used to remove variables or interaction terms from that

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multivariable model that had p>0.05. For the purposes of this analysis, PAM score was removed from the model; this prevented self-activation, highly related to the construct of parent activation [12], from capturing the variance from all other variables. HSCT-CHESS intervention arm was controlled for in the multivariable model. All other variables that were significantly associated with Parent-PAM score were tested for collinearity using variance inflation factors (VIF).

To address the possibility that Parent-PAM data at 6 months may have been missing not at random (MNAR), we stratified the final model by the extent and causes of missing data, defining strata as follows: (1) those with missing data due to a medical reason and (2) those with complete data or those with missing data not due to a medical reason. The stratified models (called pattern mixture models, PMM) [31] assume the data are missing at random (MAR) within strata. We compared stratified to unstratified models using likelihood ratio tests to assess for the presence of MNAR. Analyses were done using SAS version 9.3 (Cary, NC).

RESULTS

Participant and Patient Characteristics

As previously reported [12], our sample included a total of 198 parent-child dyads at baseline. Six months after HSCT, the sample included 139 parent-child dyads with evaluable Parent-PAM scores. The mean parent age at baseline was 38.5 years (SD=7.9) and 81.8% were mothers; the mean child age was 8.7 years (SD=5.7) and 43.9% were female (Table 1). Parents who completed the 6-month Parent-PAM were more likely to have higher incomes (p=0.009) and private insurance at baseline (p=0.0002). There were no other differences in demographic or clinical characteristics by completion status.

Over the course of the 6 months post-HSCT 35.3% (n=49) children experienced early complications, 18.7% (n=26) developed cGVHD, and 70.5% (n=98) experienced systemic infection. Eleven children (7.9%) experienced a drop in their insurance coverage.

Univariate Associations with Parent-PAM Scores Throughout the HSCT Course

Univariate analyses of associations between Parent-PAM score and factors selected by *a priori* hypotheses are summarized in Table 2. Throughout the HSCT course, Parent-PAM scores were significantly associated (p<0.1) with time, parent age, marital status, the parent's self-activation (PAM score), causal diagnosis, and HSCT type. Parent education, child age, parent general health, and the child's general health were not associated with Parent-PAM scores. Significant interactions were observed between time and each of the following variables: parent emotional functioning, log duration of the child's illness, and drop in insurance. In contrast, we did not find significant interactions between time and parent social support, early complications, cGVHD, or any systemic infection.

Multivariable Repeated Measures Model for Parent-PAM Scores

Based on backwards elimination criteria, causal diagnosis and HSCT type were removed from the multivariable model. Results of the likelihood ratio test comparing the PMM to the

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repeated measures model did not indicate the presence of MNAR (χ^2 (11)=14.1, p=0.28); beta estimates and standard errors for the final model are based on the multivariable repeated measures model. There was no indication of colllinearity in the model (all VIFs<2.0).

Parent age and marital status had constant effects on Parent-PAM scores over time, while the effects of parent emotional functioning, duration of illness, and drop in insurance changed over time as indicated by significant interactions with time (Table 2, Figure 1). Throughout the HSCT course, older parent age (β=−0.29, p=0.02) was associated with lower Parent-PAM scores, while higher Parent-PAM scores were significantly associated with never being married (vs. married, β=12.27, p=0.03). Higher parent emotional functioning scores were not associated with activation at baseline, but became important at 6 months (baseline: β=−0.002, p=0.96; interaction: β=0.14, p=0.03). At baseline longer duration of illness was associated with increased activation, but this effect diminished over time (baseline: β=3.29, p=0.0002; interaction: β=−2.40, p=0.02). Activation levels dropped for parents of children who went from private to public insurance (baseline: β=2.95, p=0.53; interaction: β=−13.82, p=0.004).

DISCUSSION

Our repeated measures model revealed the dynamic nature of factors associated with parent activation (as measured by the Parent-PAM) in the first six months following HSCT. The effects of parent age and marital status on Parent-PAM score were consistent over time. However, we found that parent's emotional functioning, length of the child's illness, and changing insurance status affected Parent-PAM scores differently at six months compared to baseline.

The association over time between higher parent activation and younger parent age was hypothesized, as an analogous relationship was observed in another study of patient activation in healthy adults [22]. Older parents may have learned that there are aspects of life that are beyond their control and this may temper their assessment of their role as a parent caregiver. Younger parents, on the other hand, may be more optimistic in their assessment.

Previous studies have not identified an association between higher activation and never being married. The results from other studies on the relationship between marital status and self-management or self-efficacy are mixed. Some studies have outlined associations between being married and better self-management of various chronic diseases [32,33], whereas other studies have found higher self-efficacy among patients who were unmarried [34] or divorced [35]. Still other studies have found no association between marital status and the self-management of chronic illnesses [36,37]. Although never married individuals consistently reported higher parent activation scores in our sample, these findings should be interpreted with caution given the small number of parents in this group (n=8). One possible explanation of this relationship is that never married parents know that they will need others' support to get through transplant and can carefully select who they can rely on and

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trust. In contrast, married parents may think that they can rely on their partner, but their partner may not always provide the needed support.

Changes in other factors associated with parent activation may reflect the impact of the child's transplant on a parent's knowledge, confidence, and ability to take action on behalf of the child's care over time. Six months post-HSCT, this impact was made evident by the emergence of factors related to the challenges and unpredictability of HSCT, such as parent's emotional functioning. This observation is supported by multiple studies that describe positive associations between emotional functioning and activated behaviors in both adult patients [1,21] and parents of chronically-ill children [38]; it may suggest that parents who feel more capable of coping with the difficulties of their child's illness over time may also feel more capable of managing their child's health state.

The association observed at baseline between the duration of the child's illness prior to HSCT and parent activation was attenuated at six months. While past experiences with illness management may translate to relatively higher levels of parent activation at the time of transplant, as all parents proceed through the HSCT treatment and recovery, they encounter the novel difficulties of HSCT, which may challenge activation. Moreover, longer duration in the more chronic phases of illness has been associated with worse parental functioning, at least partially explained by the relentlessness of necessary vigilance and the toll of unexpected complications or exacerbations [39]. Although duration of illness and causal diagnosis may be associated in some cases (e.g., newly acquired aplastic anemia versus multiply relapsed ALL), there are many instances where duration of illness can be similar between for malignancies and non-malignancies. It is important to understand what each child and family is dealing with and what supports the family needs to meet the caregiving demands.

The significant interaction between time and changing from private to public insurance at six months indicates that insurance change is related to lower parent activation scores. While previous studies of pediatric care have described the pernicious effect of losing insurance on worsened parent management [40,41], we are unaware of studies that link the *change* in insurance to altered parenting behaviors. These results suggest that changing from private to public insurance may negatively influence a parent's perception of their ability to manage their child's illness. Within the US healthcare system, changing from private to public insurance may be associated with worsening severity of disease (related to the Medicaid Spend Down) or changes in employment and the resulting loss of private insurance. However, with the health insurance reforms resulting from the Affordable Care Act, dropping from private to public insurance will be less of an issue going forward as spending caps are eliminated [42].

Many of the factors we hypothesized would be associated with parent activation were not significantly related to the construct. As summarized in our baseline analysis [12], previous studies have outlined relationships between patient activation and general health, education, and insurance status, while studies of PSE have outlined associations between PSE, the child's age, and the child's general health. We found no significant associations between parent activation and any of these factors before or at 6 months after HSCT. Our analysis

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also found no relationship between social support and parent activation, although a recent study reported that individuals with diabetes who reported stronger structural and functional support networks scored higher on the PAM [43]. These discrepancies may reflect differences in factors associated with activation on one's own health versus activation on behalf of one's child's health. Further studies are needed to understand the relationship between parent activation and types of social support and other factors.

Additionally, no variables directly pertaining to the difficulty of the HSCT recipient's clinical course were significantly associated with parent activation in our final model. In univariate analysis, neither early complications nor cGVHD was not associated with lower parent activation. Acute and chronic GVHD have been shown to be associated with significantly worse HRQL in both adult and pediatric recipients [44,45]. Although we hypothesized that clinical complication of HSCT would challenge a parent's confidence in their ability to care for their child post-HSCT and require adaptation to a novel management paradigm, we were surprised by its lack of effect on parent activation. As a gap in the literature exists concerning the impact of a changing clinical course on activation, we feel further studies are needed to understand the relationship between important clinical events and both patient and parent activation.

Over time, unrelated donor transplants and other alternative donors have become more common, reflecting an increase in the donor pool as well as increased comfort and success in applying this treatment to children with malignant and non-malignant conditions. However, complications (e.g., GVHD) are higher in the unrelated donor setting than in the autologous setting. Our prior work shows that parent emotional functioning is adversely affected by transplant complications [46]. The current analysis shows that parent activation is adversely affected by longer duration of illness in addition to discrete complications. In combination, these data suggest that parents' ability to maintain their own functioning and caregiving role is compromised when faced with the child's continued health threats and complications. Even though these parents may seem as the "experienced" ones, they still need our continued support.

We acknowledge this study's limitations. Foremost, these results should be interpreted with caution because they reflect only the data of individuals who completed the PAM and Parent-PAM at the six month assessment period (N=139). Moreover, individuals who did not complete the PAM and Parent-PAM (N=59) were more likely to have lower income and public insurance; as discussed, these factors have been shown to predict lower activation in other populations [22]. Although we did not find that data were MNAR, further studies are required to specifically address parent activation in populations with less financial resources over time. Further validation studies of the Parent-PAM in parents of children with other illnesses would also guide researchers in determining whether or not our results are generalizable across populations.

In sum, we reveal the collage of factors associated with parent activation in a population of parents as they negotiate the first six months after pediatric HSCT. Many interventions focus on changing an individual's activation or self-efficacy regarding a particular chronic condition, but may ignore clinical, social, and perspective changes, which may influence the

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individual's ability to manage their child's care. Our results suggest that adaptive interventions for improving parent activation, which respond to pertinent events, may be indicated in some populations. For example, in the context of pediatric HSCT, parents of a child with a short duration of illness prior to HSCT might require additional support initially concerning the importance of their role in caring for their child. In the six months after HSCT, parents who have poor emotional functioning or lost private insurance coverage might receive greater benefit from efforts to improve activation. Potentially, our results call for much greater attention to activation in ill populations with a rapidly fluctuating clinical course and the central role parent caregivers play for their ill children.

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Appendix 1

HSCT-CHESS

Central Project Staff

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City of Hope, Duarte, CA: Sunita Patel, PhD, Principal Investigator; Joseph Rosenthal, MD, Site Consultant; Colleen Keilty, Study Coordinator.

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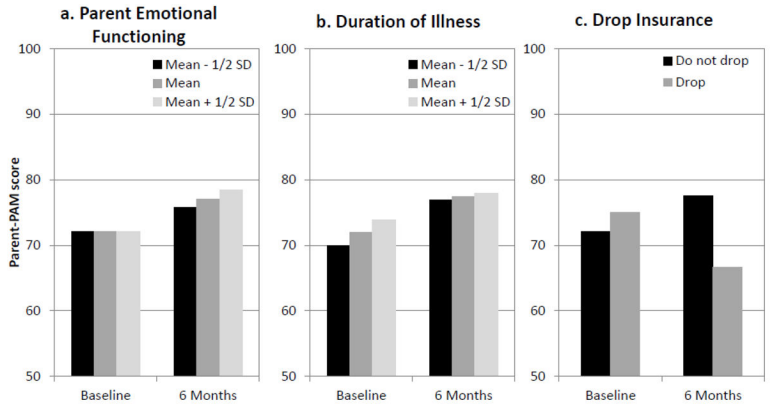

Fig. 1. Factors with Changing Effects on Parent-PAM Scores Over Time

Note: Mean parent emotional functioning at baseline was 50 (SD=20); mean log duration of illness was 2.7 (SD=1.2). Other factors set to reference or mean value.

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Table 1

Baseline demographic and clinical characteristics of HSCT recipients and their parents

	Mean (SD) or n (%) or median (25th–75th percentile)
Parent Demographic Characteristics	
Age in years, mean (SD)	38.5 (7.9)
Gender, n (%)	
Female	162 (81.8%)
Male	36 (18.2%)
Race/ethnicity, n (%)	
White, Non-Hispanic	138 (71.5%)
Non-White, Non-Hispanic	25 (13.0%)
Hispanic	30 (15.5%)
Education level, n (%)	
High school graduate or less	54 (27.3%)
Some college or more	144 (72.7%)
Marital status, n (%)	
Married/Living with partner	166 (83.8%)
Divorced/separated/widowed	24 (12.1%)
Never married	8 (4.0%)
Household income, n (%)	
<$40K	66 (33.5%)
$40K–$59K	31 (15.7%)
$60K–$79K	27 (13.7%)
>$80K	73 (37.1%)
Primary caregiver's job status, n (%)	
Full-time	88 (44.4%)
Part-time	22 (11.1%)
Homemaking	88 (44.4%)
Child Demographic Characteristics	
Age in years, mean (SD)	8.7 (5.7)
Gender, n (%)	
Female	87 (43.9%)
Male	111 (56.1%)
Insurance type at baseline, n (%)	
Private	134 (68.0%)
Public	63 (32.0%)
Clinical Characteristics	
Duration of illness in months, median (25th–75th percentile)	11 (6–41)
Causal Diagnosis, n (%)	
Non-malignancy	76 (38.4%)
Malignancy, no prior relapse	77 (38.9%)

	Mean (SD) or n (%) or median (25^{th}–75^{th} percentile)
Malignancy, prior relapse	45 (22.7%)
Site of pre-transplant care, n (%)	
Local, at transplant site	79 (40.3%)
Referred from another institution	117 (59.7%)
Transplant type, n (%)	
Autologous	50 (25.3%)
Allogeneic-related	38 (19.2%)
Allogeneic-unrelated	110 (55.6%)
Prior HSCT, n (%)	9 (4.6%)

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Table 2

Univariate and multivariable repeated measures analysis for Parent Activation (Parent-PAM) in 6 months following HSCT

	Univariate		Multivariable[a]	
	β (se)	p-value	*β (se)*	p-value
Time				
Baseline (reference)				
6 months	5.00 (1.29)	0.0001	4.76 (4.65)	0.31
Baseline Parent and Child				
Demographic Characteristics				
Parent age	−0.29 (0.12)	0.02	−0.29 (0.12)	0.02
Parent's education level				
High school graduate or less (reference)				
Some college or more	−1.61 (2.22)	0.47		
Marital Status				
Married/living with partner (reference)				
Divorced/separated/widowed	−3.01 (2.92)	0.30	−3.0 (2.92)	0.31
Never married	16.13 (5.13)	0.002	12.27 (5.50)	0.03
Child age	−0.11 (0.17)	0.53		
Parent Well-being at Time of Assessment				
Parent emotional functioning	−0.01 (0.05)	0.78	−0.002 (0.05)	0.96
Time*Parental emotional functioning	0.15 (0.07)	0.02	0.14 (0.06)	0.03
Parent general health	−0.01 (0.04)	0.70		
Parent social support	0.07 (0.05)	0.16		
Time* Parent social support	−0.01 (0.06)	0.86		
Self Activation (PAM Score)	0.53 (0.04)	<0.0001		
Baseline Clinical Characteristics				
Causal Diagnosis				
Non-malignancy (reference)				
Malignancy, no prior relapse	−6.42 (2.20)	0.004		
Malignancy, prior relapse	−3.11 (2.55)	0.22		
Log duration of illness in months	3.23 (0.87)	0.0003	3.29 (0.88)	0.0002
Time*Log duration of illness in months	−3.01 (1.01)	0.003	−2.40 (0.98)	0.02
Transplant type				
Autologous	−1.71 (2.35)	0.47		
Allogeneic-related	−4.54 (2.60)	0.08		
Allogeneic-unrelated (reference)				
Uncontrollable Difficulty of Transplant				
Early complications[b]	3.02 (2.26)	0.18		

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	Univariate		Multivariable[a]	
	β (se)	p-value	*β (se)*	p-value
Time*Early complications	1.12 (2.70)	0.68		
CGVHD[c]	0.12 (2.93)	0.97		
Time*CGVHD	−2.80 (3.34)	0.40		
Infection [d]	2.36 (2.41)	0.33		
Time*Infection	−0.29 (2.84)	0.92		
Parent rating of child's general health at time of assessment	0.01 (0.03)	0.72		
Drop in insurance[e]	5.30 (4.81)	0.27	2.95 (4.65)	0.53
Time*Drop in insurance	−14.48 (4.84)	0.003	−13.82 (4.68)	0.004

[a] Multivariable model controls for HSCT-CHESS intervention

[b] aGVHD of grade 2 or higher or intermediate or poor toxicity by 3 months

[c] Limited or extensive cGVHD by 6 months

[d] Systemic Infection by 6 months

[e] Change from private insurance at baseline to public insurance at six months