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# Parental Efficacy and Control Questionnaire in Hematopoietic Stem Cell Transplant: Preliminary Validation

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## Abstract

**Objective** Develop and evaluate the preliminary validity of a self-report measure of parents' treatment-related efficacy and control, Parental Efficacy and Control Questionnaire-Hematopoietic Stem Cell Transplant (PECQ-HCT), in a pediatric HCT sample. **Methods** Participants included 185 parents of children ($\leq$12 years old) receiving HCT participating in a larger, longitudinal study. Parents completed the PECQ-HCT as well as measures of social problem-solving skills, collective family efficacy, family beliefs, and parental distress. **Results** Exploratory factor analysis results indicated that a 37-item four-factor model was the best fitting and most theoretically sound, $\chi^2(df = 1,596) = 14,089.95$, $p < .01$, comparative fit index = 0.92, Tucker–Lewis Index = 0.90, and root mean square error of approximation = 0.07. Preliminary subscale scores demonstrated adequate internal consistency as well as good content and criterion-related validity. **Conclusions** If replicated using a confirmatory factor analysis in a separate sample, these findings suggest that the four-factor PECQ-HCT measure may be useful for measuring HCT-related parental efficacy and perceived control.

**Key words**: exploratory factor analysis; hematopoietic stem cell transplant; parent; Parental Efficacy and Control Questionnaire; pediatric.

## Introduction

Hematopoietic stem cell transplantation is an increasingly common treatment for pediatric patients with a wide range of once incurable and fatal immunological, hematological, and oncological diagnoses (D'Souza, Lee, Zhu, & Pasquini, 2017). Hematopoietic stem cell transplant (HCT) begins with a prolonged hospital stay that is followed by an intensive outpatient regimen composed of frequent outpatient medical appointments and a complex medication regimen necessary to minimize the risk for morbidity and mortality. Throughout HCT, parents repeatedly encounter novel and sometimes unpredictable environments (e.g., hospital room, temporary housing), treatments (e.g., ablative chemotherapy), symptoms (e.g., mucositis, graft versus host disease), and medical staff (e.g., new nurses, medical trainees) that potentially undermine the development of efficacy in caring for one's child (i.e., parental efficacy). Based on a large and robust body of efficacy literature (Aika, Ito, & Yamamoto, 2017; Barlow, Shaw, & Wright, 2000;

Harper et al., 2013; Knibb, Barnes, & Stalker, 2015; Noser, Patton, Van Allen, Nelson, & Clements, 2016), the prolonged and repeated challenges to parental efficacy during HCT could be an important mechanism contributing to increased distress among parents of children undergoing HCT (Packman, Weber, Wallace, & Bugescu, 2010; Phipps, Dunavant, Lensing, & Rai, 2004).

Efficacy, a central construct of Bandura's Social Cognitive Theory, is the belief that one has the ability to achieve a desired or intended outcome through one's actions (Bandura, 1997). Efficacy beliefs are influenced by expectations and social support. An individual's expectations about how events are associated and the consequences of one's actions shape one's efficacy (Bandura, 1997, 2001). Parental expectations during HCT are repeatedly undermined by unexpected infections, intractable side effects, and, sometimes, unexpected changes in child behavior and family relationships. Similarly, social support is central to developing and maintaining efficacy (Bandura, 2001; Benight & Bandura, 2004; Schwarzer & Knoll, 2007). Unfortunately, previous social support systems can be difficult for parents to access during HCT, magnifying the importance of support from, and communication with, the child's medical team.

Notably, research in other pediatric populations shows that parents with greater treatment-related efficacy report lower parental stress, anxiety, and psychological distress (Aika et al., 2017; Barlow et al., 2000; Harper et al., 2013; Knibb et al., 2015; Noser et al., 2016). Similarly, parental efficacy in supporting one's child during treatment procedures for cancer was associated with lower child distress and higher child cooperation (Peterson et al., 2014). Despite this consistent evidence linking treatment-specific parental efficacy with parent distress in other pediatric populations, no measure has been developed to assess HCT-related parental efficacy.

Although it is often preferable to use previously validated measures, the nature of efficacy requires situationally and task-specific measures (Bandura, 2006a, 2006b). Items from previously validated measures of parental efficacy for other pediatric medical population were reviewed including measures for parents of infants in the neonatal intensive care unit (e.g., "I know characteristics/behaviors common to premature babies in NICU"; Melnyk, 1995; Melnyk, Oswalt, & Sidora-Arcoleo, 2014; Melnyk et al., 2004), children with asthma (e.g., "How sure are you that you can help your child prevent a serious breathing problem?"; Bursch, Schwankovsky, Gilbert, & Zeiger, 1999), children with diabetes (e.g., "Being the one in charge of giving insulin to your child"; Streisand, Swift, Wickmark, Chen, & Holmes, 2005), and cancer (only a six-item measure including, "hiding emotions from

their child if parent becomes upset"; Peterson et al., 2014). However, none adequately reflected the situations and tasks that confront parents of children undergoing HCT.

Therefore, the goal of the current study is to address this important measurement gap by developing and reporting the preliminary psychometric properties of a novel self-report measure of HCT-related parental efficacy and perceived control: Parental Efficacy and Control Questionnaire-Hematopoietic Stem Cell Transplant (PECQ-HCT). We hope that this measure can ultimately assist healthcare providers to identify and effectively promote parental efficacy in order to support parents' emotional functioning so that they can, ultimately, optimize their child's emotional and health outcomes following HCT. The specific aims of the current study were to (a) develop a novel self-report measure of parents' HCT-treatment efficacy and perceived control, (b) identify the factor structure of the PECQ-HCT by conducting an exploratory factor analysis (EFA), (c) examine convergent and discriminant validity by correlating the PECQ-HCT factors with constructs previously associated with parental efficacy, and (d) evaluate criterion-related validity by examining the associations between PECQ-HCT factor(s) at baseline and parental distress at 1-month follow-up. Specifically, all PECQ-HCT factors were expected to be significantly and negatively associated with parent psychological distress at the baseline and 1-month follow-up (Barlow et al., 2000). All PECQ-HCT factors were also expected to be correlated positively with baseline general family efficacy (Caprara, Regalia, Scabini, Barbaranelli, & Bandura, 2004), negatively with baseline family illness beliefs (Knibb et al., 2015), and positively with baseline family problem solving (Noser et al., 2016).

## Methods

### Participants
Participants were 185 parents (i.e., an adult primary caregiver) of children who received a HCT. Parents were eligible for the study if their child had received a HCT, was ≤12 years of age, was ≤2 weeks postdischarge from the hospital, and was prescribed an oral and/or an IV medication regimen at discharge. Parents and children needed to be fluent in English to participate. Parents were ineligible for the study if the parent's cognitive status or the child's medical status precluded the completion of questionnaires (as determined by the electronic medical record or medical team report). The majority of parents were Caucasian ($n = 144$; 78.4%) and mothers ($n = 163$; 88.1%). Mean parent age was 34.85 years ($SD = 7.71$). The median educational attainment of parents was attending some education at college or vocational school

**Table I.** Descriptive Statistics for Demographic Characteristics ($n = 185$)

| Variable | Frequency | Percent |
|---|---|---|
| Parent sex, female | 168 | 90.8 |
| Parent race/ethnicity | | |
|   Caucasian | 145 | 78.4 |
|   African American | 16 | 8.7 |
|   Hispanic/Latino | 8 | 4.3 |
|   Other | 16 | 8.6 |
| Education | | |
|   Less than high school | 14 | 7.6 |
|   High school degree/GED/some college/ vocational school | 81 | 43.8 |
|   College degree/vocational school/some professional/graduate school | 55 | 29.7 |
|   Graduated professional/graduate school | 32 | 17.3 |
| Household income | | |
|   <$19,999 | 48 | 25.9 |
|   $20,000–$39,999 | 31 | 16.8 |
|   $40,000–$79,999 | 53 | 28.7 |
|   >$80,000 | 42 | 22.7 |
| Relationship to patient | | |
|   Mother | 163 | 88.1 |
|   Father | 16 | 8.7 |
|   Other | 6 | 3.2 |

*Note.* Three (1.6%) parents did not report education and 11 (5.9%) did not report household income. GED = Graduate Education Diploma.

($n = 50$, 27%) and the median household income was $40,000–$59,999 ($n = 27$; 14.6%). Children's ages ranged from 3 months to 12 years ($M = 5.03$, $SD = 3.50$). Children's diagnoses included immune deficiency ($n = 47$, 25.4%), malignancy ($n = 80$, 43.2%), bone marrow failure ($n = 53$, 28.6%), metabolic disease ($n = 4$, 2.3%), and missing ($n = 1$, 0.5%). See Table I for a detailed summary of demographic information.

## Study Procedure

The current study is part of a larger, longitudinal, observational dataset examining medication adherence in children receiving HCT. Parents of children who had received a HCT were recruited from three geographically diverse children's hospitals. Recruitment methods and study protocols were consistent across study sites. The study was approved by the Institutional Review Boards at all three hospitals. Families who met initial eligibility criteria were identified by the HCT medical teams at the respective hospitals through inpatient rosters. Families were then approached for participation by a member of the study team while still hospitalized or within 2 weeks of being discharged. After providing written informed consent, parents completed self-report measures (baseline ratings). Parents completed follow-up self-report measures 1 month later (1-month follow-up ratings). Parents were provided monetary compensation for their time and effort. A total of 238 families were

approached for participation between 2013 and 2018 of which 185 families (78%) agreed to participate. There were no differences in child age or gender between families that participated versus declined to participate in the study. A total of 135 families (73%) completed baseline after discharge from the hospital. PECQ-HCT scores were not significantly different between families who completed baseline questionnaire before or after they discharged from the hospital. A total of 161 families (87%) completed the 1-month follow-up. There were also no significant differences in parent age, gender, race, or annual income between families that completed both time points and those who only completed baseline.

## Measure Development Procedures: The PECQ-HCT

Items for the PECQ-HCT were developed by a multidisciplinary psychosocial team that served the HCT unit at a Midwestern hospital. The team consisted of two psychologists who specialize in providing psychological care to patients receiving HCT and their families, two psychology fellows, a nurse, and two social workers. First, the team reviewed the literature and examined existing measures of general parental efficacy (Campis, Lyman, & Prentice-Dunn, 1986; Johnston & Mash, 1989) and parental efficacy in pediatric populations (Bursch et al., 1999; Melnyk, 1994; Melnyk et al., 2004; Peterson et al., 2014; Streisand et al., 2005). No existing measure specific to the pediatric HCT population was identified. Therefore, the study team generated a list of themes based on Bandura's Social Cognitive Theory (Bandura, 1997), existing pediatric literature, and clinical experience including, perceived efficacy for specific care tasks, expectations, illness beliefs, and support. Item development was guided by coverage of these four themes which would be represented by a corresponding subscale. The number of items generated for each theme was not predetermined. The initial list generated by the team included themes about interacting with the medical team, living in the hospital, caring for their child in the hospital and outpatient treatment. Items were generated to capture common themes that parents often report to the psychosocial care team while their child was admitted for HCT and shortly after discharge. The items were then edited for clarity, face validity, and to avoid multiple items assessing the same concept. This process resulted 73 items for the PECQ-HCT measure that parents rated on a 4-point Likert-type scale (1, strongly disagree; 2, somewhat disagree; 3, somewhat agree; 4, strongly agree). The readability of the resulting measure is a Flesch–Kincaid Grade Level of 4.2.

## Validation Measures
### Demographic Information
Parents provided demographic information including their age, sex, race/ethnicity, highest level of education completed, total household income, and relationship to the child. Parents also provided their child's age and diagnosis.

### Brief Symptom Inventory
The Brief Symptom Inventory (BSI) is a 53-item self-report measure of psychological distress (Derogatis, 1993). Parents are asked to rate the degree to which a range of psychological symptoms have bothered them in the past week on a 5-point Likert-like scale (0 = not at all to 4 = extremely). The BSI yields nine subscale scores (Somatization, Obsessive–Compulsive, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation, and Psychoticism) as well as a global severity index (an indicator of parent psychological distress). Only the global severity index was used in the current study with higher scores reflecting greater levels of distress. Scores were transformed into $T$-scores based on non-patient adult norms ($M = 50$, $SD = 10$). $T$-scores $\geq 63$ are considered clinically significant. Previous research has shown the BSI to demonstrate good test–retest reliability and high construct validity (Derogatis, 1993). The BSI has also been used in research with parents of children with cancer (Bonner, Hardy, Willard, & Hutchinson, 2007). Cronbach's αs in this sample demonstrated excellent internal reliability at both baseline ($α = .96$) and 1-month follow-up ($α = .97$).

### Social Problem-Solving Inventory-Revised Short Form
The Social Problem-Solving Inventory-Revised Short Form (SPSI-R:SF; D'Zurilla, Nezu, & Maydeu-Olivares, 2002) is a 25-item measure of parents' problem-solving skills. Parents rate items on a 5-point Likert-type scale from 0 (not at all true of me) to 4 (extremely true of me). The SPSI-R:SF consists of five subscales (Positive Problem Orientation, Rational Problem Solving, Negative Problem-Solving Orientation, Impulsivity/Carelessness Style, and Avoidance Style) that each include five items which are averaged to yield a subscale score. Of note, three subscale scores are reverse coded (Negative Problem-Solving Orientation, Impulsivity/Carelessness Style, and Avoidance Style). Subscale scores are then summed to compute a total score. Only the SPSI-R:SF total score was used in the current study with higher scores reflecting more effective social problem-solving abilities. The SPSI-R:SF has demonstrated strong psychometric properties and has previously been used in caregivers of adults with cancer (D'Zurilla et al., 2002; Ko et al., 2005). Internal consistency within our sample was good ($α = .83$).

### Perceived Collective Family Self-Efficacy
The 20-item Perceived Collective Family Self-Efficacy (PCFE; Caprara et al., 2004) is a measure of participants' perception of their family's collective ability to work effectively to complete tasks necessary for family functioning (e.g., communication and roles). Individual items are rated on a 7-point Likert-like scale ranging from 1 (not well at all) to 7 (very well). Items are averaged to compute a total score. Higher scores reflect higher perceived ability for the family to work together to manage daily routines, make decisions, cope with adversity, and complete tasks. Previous studies have shown the PCFE to demonstrate strong internal consistency ($α = .96$–.97; Caprara et al., 2004). The Cronbach's α within our sample was excellent ($α = .94$).

### Psychosocial Assessment Tool
The Psychosocial Assessment Tool (PAT 2.0; Pai et al., 2008) is a brief screening tool, completed by parents, to measuring psychosocial risk in families of newly diagnosed children within seven domains (e.g., Family Social Support, Child Problems, and Family Beliefs). Only the four-item Family Beliefs subscale was used to measure family beliefs about the global impact of their child's illness on family adjustment and their optimism about a positive treatment outcome. Items are scored dichotomously to indicate either risk (1) or no risk (0) and then averaged to generate a subscale score. Higher scores are indicative of more negative family beliefs. The PAT 2.0 has strong psychometric properties (Kazak et al., 2018; Pai et al., 2008). Internal reliability within this sample was excellent ($α = .96$).

### Overview of Statistical Analyses
Frequency counts for response categories of the 73 items within the PECQ-HCT measure (see Supplementary Table I) were first assessed to examine variability in the item response distributions (i.e., to ensure that at least three of four response categories were being used). Fifteen items were removed due to restricted response variability with participant responses limited to one or two response options (e.g., "somewhat agree" or "strongly agree"; "somewhat disagree" or "strongly disagree") indicating that these items were uninformative. An additional item was removed due to its similarity with another item, "What to do if the medication causes other side effects." This resulted in a total of 57 PECQ-HCT items being included in the EFAs (see Supplementary Table I for all 73 items). Given the recommendations of Schmitt (2011), an EFA specifying one to seven factors and using a weighted least squares mean and variance adjusted estimator (appropriate for ordered categorical response options) with geomin (oblique) rotation was

conducted in Mplus 8.2 (Muthén & Muthén, 2017). To determine how many factors to retain, we looked for eigenvalues >1 in addition to goodness of fit indices. Specific goodness of fit indices and cutoffs were root mean square error of approximation (RMSEA) < 0.08, comparative fit index (CFI) > 0.90, Tucker–Lewis Index (TLI) > 0.90, and standard root mean square residual (SRMR) < 0.08 (Hu & Bentler, 1999). Items were determined to load on a factor if they independently loaded on one factor with a factor loading of ≥|0.30|. Items with multiple factor loadings of ≥|0.30| were still retained if one of their factor loadings was ≥|0.2| than their loadings on any other factor. We also confirmed that all residual item variances were positive.

Based on the EFA results, subscale scores were computed. Internal consistency based on Cronbach's α for the subscale scores were calculated. Correlational analyses to evaluate convergent and discriminant validity between PECQ-HCT scores and other standardized measures of similar constructs collected at baseline. Criterion-related validity was evaluated via correlations between baseline PECQ-HCT scores and parental distress at 1-month follow-up.

## Results

### Exploratory Factor Analysis

Results from the EFA including 57 items ($\chi^2[df = 1,596] = 14,089.95, p < .01$) indicated that the 1-factor model (RMSEA = 0.10; CFI = 0.76; TLI = 0.75; SRMR = 0.21), 2-factor model (RMSEA = 0.08; CFI = 0.85; TLI = 0.84; SRMR = 0.16), and 3-factor model (RMSEA = 0.07; CFI = 0.90; TLI = 0.88; SRMR = 0.13) were a poor fit to the data. Fit indices for the 4-factor model indicated an acceptable fit (RMSEA = 0.07; CFI = 00.92; TLI = 0.90; SRMR = 0.12) and fit indices for the 5-factor model indicated a slightly improved fit (RMSEA = 0.06; CFI = 0.94; TLI = 0.92; SRMR = 0.10). However, examination of the eigenvalues and pattern of item loadings revealed that the 4-factor model was the most parsimonious and theoretically sound model as no items loaded strongly (i.e., >|0.30|) on two of the five factors within the 5-factor solution.

Examination of the 4-factor model reflected a total of 37 items to meet predetermined criteria to be included in the final PECQ-HCT subscale solution such that they had a unique strong factor loading (≥|0.30|) or a clearly dominant loading if they loaded on numerous factors (difference between strongest factor loading and next factor loading of ≥|0.20|). The remaining 20 items of the original 57 included in the EFA were eliminated from the PECQ-HCT subscale solution as they did not meet the predetermined criteria. Notably, eliminated items included those reflecting HCT experiences (e.g., I can do a lot to prevent my child from getting infections). Of the retained 37 items, 25 loaded strongly (>|0.30|) on a single factor and an additional 12 items had cross-loadings on several factors, but with a clear dominant factor (see Table II). Factor 1 (Medical Locus of Control; eight items) pertained to global parental efficacy. Factor 2 (Treatment-Specific Efficacy) included 13 items pertaining to parents' perception of their ability to care for specific needs of their child. Eight items whose content included perceived support and communication with others loaded on Factor 3 (Perception of Support). Factor 4 included eight items regarding parental perception of the appropriateness of (and efficacy to adjust) treatment components (Expectations of Allied Health).

### PECQ-HCT Descriptive Statistics

Subscale scores were calculated by taking the mean of the items within that subscale (see Supplementary Table II for descriptive statistics). Items with negative factor loadings (items 10, 14, and 22) were reversed scored. Internal consistency was high for the Treatment-Specific Efficacy subscale, Perception of Support subscale, and Expectations of Allied Health subscale at baseline and 1-month follow-up (see Supplementary Table II). Cronbach's αs for Medical Locus of Control subscale reflected marginal internal consistency at baseline ($\alpha = .64$) and slightly improved internal consistency at 1-month follow-up ($\alpha = .70$). Small significant correlations were observed across all subscales ($p < .05$) except for the relationship between Medical Locus of Control (Factor 2) and Expectations of Allied Health (Factor 4), $r = .12, p = .12$. PECQ-HCT subscale scores demonstrated high test–retest reliability (all correlations >.50; see Supplementary Table III).

### Validity Analyses

Concurrent convergent validity was demonstrated by significant small correlations between the baseline PECQ-HCT Medical Locus of Control, Treatment-Specific Self-Efficacy, Perception of Support, and Expectations of Allied Health subscales and baseline parental distress (BSI), and collective family efficacy beliefs (PCFE; see Table III; Cohen, 1992). Small significant associations between parents' problem-solving skills at baseline (SPSI-R:SF) with baseline PECQ-HCT Medical Locus of Control, Treatment-Specific Efficacy, and Expectations of Allied Health subscales also provided preliminary concurrent convergent validity. A nonsignificant correlation between parents' problem solving and the PECQ-HCT Perception of Support subscale provided initial evidence of discriminant validity; examination of the face validity of the items on Perception of Support subscale appears to assess efficacy in communication rather

**Table II.** *Items Retained and Factor Loadings for the Parental Efficacy and Control Questionnaire-Hematopoietic Stem Cell Transplant Measure Based on EFA*

| Items | Factor 1 | Factor 2 | Factor 3 | Factor 4 |
|---|---|---|---|---|
| Factor 1: Medical Locus of Control | | | | |
| 8. I can reach my child's doctor by phone or email when I need to. | 0.77 | | | |
| 9. I can reach my child's nurse by phone or email when I need to. | 0.76 | | | |
| 20. I have the ability to influence how my child feels about himself/herself. | 0.75 | | 0.31 | |
| 21. I can influence how my child feels about his/her medical condition. | 0.72 | 0.31 | | |
| 18. I can do a lot to prevent my child from getting infections. | 0.49 | | | |
| 22. Whether my child stays healthy or not is just a matter of fate. | −0.47 | | | |
| 10. Whether my child avoids infections is just a matter of luck. | −0.47 | | | |
| 14. My child's health is largely a matter of fortune. | −0.46 | | | |
| Factor 2: Treatment-Specific Efficacy | | | | |
| 31. I know… What to do if the medication causes a tummy ache. | 0.37 | 0.91 | | |
| 27. I know… What to do when my child is feeling sick to his/her stomach. | 0.40 | 0.85 | | |
| 29. I know… What to do if the medication causes side effects. | 0.95 | 0.82 | | |
| 30. I know… How to help my child if his/her medication tastes bad to him/her. | | 0.81 | | |
| 28. I know… What to do if my child is having difficulty swallowing medication. | | 0.80 | | |
| 54. I can make my child feel better when he/she is… Feeling sick to his/her stomach. | 0.39 | 0.74 | | 0.32 |
| 52. I can make my child feel better when he/she is… In pain. | 0.38 | 0.71 | | 0.31 |
| 35. I know… What to do when my child doesn't want to eat or loses his/her appetite. | 0.45 | 0.66 | | 0.39 |
| 25. I know… What kind of behavior to expect from my child when we are at home. | | 0.50 | | |
| 24. I know… What kind of changes to expect in my child when he/she is in the hospital. | | 0.48 | | |
| 2. I am clear with the medical staff that I know what is best for my child | | 0.41 | | |
| 13. I believe that I can tackle any problems with my child. | | 0.36 | | |
| 12. I can approve OR decline any treatments offered to my child. | | 0.33 | | |
| Factor 3: Perception of Support | | | | |
| 47. My child's nurses… Listen to me. | | | 0.97 | |
| 48. My child's nurses… Understand my concerns. | | | 0.91 | |
| 46. My child's nurses… Listen to my child. | | | 0.88 | |
| 49. My child's nurses… Feel that I know how to care for my child's health care needs. | | | 0.87 | |
| 50. My child's nurses… Know how to take good care of him/her. | | | 0.86 | |
| 51. My child's nurses… Use language that I can understand. | | | 0.71 | 0.35 |
| 45. My child's nurses… Understand my child's medical condition. | | | 0.45 | |
| 65. I feel comfortable… Asking others for help. | | | 0.36 | |
| Factor 4: Expectations of Allied Health | | | | |
| 70. Outpatient treatment right amount of: Physical therapy. | | | | 0.97 |
| 71. Outpatient treatment right amount of: Occupational therapy. | | | | 0.97 |
| 72. Outpatient treatment right amount of: Therapy from a psychologist. | | | | 0.85 |
| 68. In hospital right amount of: Therapy from a psychologist. | | | | 0.79 |
| 66. In hospital right amount of: Physical therapy. | | 0.55 | | 0.78 |
| 67. In hospital right amount of: Occupational therapy. | | 0.56 | | 0.77 |
| 73. Outpatient treatment right amount of: Time with a child life specialist. | | | | 0.70 |
| 69. In hospital right amount of: Time with a child life specialist. | | 0.35 | | 0.67 |

*Note.* EFA = exploratory factor analysis. Only included factor loadings ≥|0.3|. The following items were removed from the measure based on the EFA results and can be found in the Supplementary Table I: 5, 19, 23, 33, 34, 36, 37, 39–42, 53, 55, 56, 58–60, and 62–64.

**Table III.** *Concurrent and Criterion-Related Validity Results for the PECQ-HCT*

| | BSI (B) | BSI (FU) | SPSI-R:SF (B) | PCFE (B) | PAT 2.0 family beliefs (B) |
|---|---|---|---|---|---|
| PECQ-HCT F1: Medical Locus of Control (B) | −0.17* | −0.15 | 0.24** | 0.20** | −0.27** |
| PECQ-HCT F2: Treatment-Specific Efficacy (B) | −0.24** | −0.19* | 0.24** | 0.31** | −0.23** |
| PECQ-HCT F3: Perception of Support (B) | −0.26** | −0.24** | 0.13 | 0.26** | −0.16* |
| PECQ-HCT F4: Expectations of Allied Health (B) | −0.26** | −0.22** | 0.20** | 0.20* | −0.13 |

*Note.* B = baseline; BSI = Brief Symptom Inventory; F = factor; FU = 1-month follow-up; PAT 2.0 = Psychosocial Assessment Tool; PECQ-HCT = Parental Efficacy and Control Questionnaire-Hematopoietic Stem Cell Transplant; PCFE = Perceived Collective Family Self-Efficacy; SPSI-R:SF = Social Problem-Solving Inventory-Revised Short Form.,
*$p < .05$;, **$p < .01$.

than one's ability to problem-solve specific tasks. Similarly, evidence for concurrent convergent validity was also observed with small but significant associations between PAT2.0 Family Beliefs subscale and PECQ-HCT Medical Locus of Control, Treatment-Specific Efficacy, and Perception of

Support. Initial evidence for discriminant validity was suggested by the nonsignificant association between the PAT 2.0 Family Beliefs subscale (i.e., perception of the impact of the disease on family relationships) and the PECQ-HCT Expectations of Allied Health (i.e., perceptions of the amount of supportive care their child is receiving). Criterion-related validity was demonstrated through the significant small to moderate sized prospective correlations between all baseline PECQ-HCT subscale scores with parental distress at the 1-month follow-up ($p < .05$) other than Medical Locus of Control.

## Discussion

Numerous factors during treatment for pediatric HCT increase parents' risk for feeling like they have little control over their child's treatment (i.e., perceived control) and lack the skills to care for their child's treatment-specific needs (i.e., HCT-related parental efficacy), particularly after discharge from the hospital. This is concerning as research within pediatric cancer and other chronic illnesses has linked treatment-related parental efficacy and perceived control with both parent adjustment (Barlow et al., 2000; Knibb et al., 2015; Norberg & Boman, 2013; Noser et al., 2016) and child health outcomes (Chiang, Huang, & Chao, 2005; Noser et al., 2016; Peterson et al., 2014). This study extends current research by developing and providing preliminary psychometric support for a novel self-report measure of HCT-related parental efficacy and control in the outpatient setting: the PECQ-HCT. Developing such a measure is critical to enabling clinicians and researchers to characterize HCT-related parental efficacy and perceived control within this population as well as examine their associations with parent and child outcomes.

Overall, results from the current study provide preliminary evidence for the PECQ-HCT being a valid and reliable questionnaire. Results from the EFA yielded a 37-item, four-factor measure that demonstrated adequate statistical fit, with superior interpretability and theoretical structure compared to other potential factor solutions. In the current sample, EFA results identified the first factor (Medical Locus of Control) to include items pertaining to parents' perception of agency in their ability to contribute to the success of their child's medical status. The second factor (Treatment-Specific Efficacy) had high factor loadings on items measuring parents' perception of their ability to care for specific needs of their child. Items pertaining to parents' perceived support and communication with others loaded on Factor 3 (Perception of Support). Finally, Factor 4 (Expectations of Allied Health) pertained to parental efficacy in influencing the appropriateness of allied treatment components.

Overall, the PECQ-HCT subscale scores demonstrated marginal to good internal reliability as well as good concurrent and criterion-related validity. Consistent with previous research in pediatric cancer (Harper et al., 2013; Peterson et al., 2014), small significant positive correlations were observed between three of the PECQ-HCT subscale scores and concurrent parental distress and parental distress at the 1-month follow-up. The Medical Locus of Control subscale demonstrated a small significant correlation with concurrent parental distress but the prospective correlation was not significant. However, further evaluation of this subscale is still warranted given significant correlations with key validation constructs including social problem-solving skills, family collective self-efficacy, and family illness beliefs. While the relationships between the PECQ-HCT and parental distress may be bidirectional, the prospective associations found here support the notion that parents' HCT-related efficacy and control contribute to their overall distress levels and may represent a target for interventions to decrease parental distress in the context of HCT. In addition, initial support for concurrent validity was demonstrated by positive associations between the Medical Locus of Control, Treatment-Specific Efficacy, and Expectations of Allied Health with parents' overall social problem-solving skills and all four PECQ-HCT subscales significantly associated with collective family efficacy.

Certainly, there are limitations that should be considered when examining the results of this study. First, parents of children undergoing HCT were not formally involved in the measure development process. Although this decision was made out of an abundance of caution for parent burden during a difficult and often chaotic time, their absence could undermine the relevance and readability of the items. In addition, all measures included in the current study were parent-report measures. While self-report measures are often considered optimal tools to assess efficacy and perceptions of control, using a single reporter for both the predictor and outcome variables results in common method variance. Future studies should consider utilizing multiinformant designs (e.g., spouse report of family efficacy) to further evaluate the validity and clinical utility of this measure. In addition, the preponderance of parents within this sample was Caucasian mothers, which limits the generalizability of our findings to other caregiver and racial groups. Additional research is warranted to examine the psychometric properties of this measure within more diverse samples as well as establish normative data for this measure. Nonetheless, data for the current study were collected at three different geographically diverse locations and yielded an economically diverse sample, which helps to support the generalizability of these findings.

Future studies should seek additional psychometric support for the PECQ-HCT including the conduct of a confirmatory factor analysis in another sample. It may also be beneficial to include hierarchical factor models to determine whether a total score is appropriate for the PECQ-HCT. In addition, interventional or experimental studies in which parental efficacy is expected to change should be conducted to evaluate the sensitivity of the PECQ-HCT. Additional research will be needed to confirm the factor structure of this measure in a separate sample of parents of children who received an HCT.

The results from the current study provide preliminary support for a novel measure of parental HCT-treatment efficacy and perceived control. Measuring parental HCT-treatment efficacy is clinically relevant given research within other pediatric chronic illness populations linking it with both parent and child outcomes (Fedele et al., 2013; Jobe-Shields et al., 2009; Phipps et al., 2004; Ryan et al., 2010). Initial results also suggest that the subscales can be used clinically to determine specific targets of intervention such as teaching parents methods to managing their child's side effects (Treatment-Specific Efficacy), reframing their child's thoughts about their medical condition in a developmentally appropriate way (Medical Locus of Control), aligning nursing communication approach to a specific parent's needs (Perceived Social Support), and aligning parental expectations for allied health care services with what their child is receiving (Expectations of Allied Health). The PECQ-HCT has the potential to facilitate future research by providing a measure of one mechanism by which parent distress increases during pediatric HCT and allow clinicians to identify relevant treatment targets to improve both parent and child outcomes within this population.

## Supplementary Data

Supplementary data can be found at: https://academic.oup.com/jpepsy.

## Funding

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