

# Development and Validation of the Parent Experience of Child Illness

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**Objective** To develop a measure of parent adjustment related to caring for a child with a chronic illness and to evaluate the reliability and validity of the measure with a group of parents of children with brain tumors. **Methods** One-hundred forty-nine parents of patients (age <1–17 years) diagnosed with a brain tumor were assessed using the 25-item self-report Parent Experience of Child Illness (PECI). Internal consistency, construct validity, and factor structure were assessed. **Results** Exploratory factor analysis yielded four theoretically coherent factors including: Guilt and Worry, Emotional Resources, Unresolved Sorrow and Anger, and Long-term Uncertainty. Internal reliability for the PEGI scales ranged from .72 to .89, suggesting acceptable reliability. As evidence of construct validity, the PEGI scales show significant, positive correlations with scales from established measures of parent adjustment. **Conclusion** The PEGI augments the current literature by providing a brief measure of parents' subjective distress and perceived Emotional Resources, domains that are critical but understudied in children with chronic illness and their caregivers.

**Key words** measure development; parent adjustment; pediatric neuro-oncology.

Consideration of parent/caregiver variables is critical when conducting research with children facing life-threatening illness, given the impact of parent functioning on child functioning. Indeed, studies of chronic illness samples over the past 25 years have consistently identified family functioning as an important predictor of psychological functioning of children with chronic illness (Finney & Bonner, 1992; Quittner & Digirolamo, 1998). Family factors in particular may serve to either exacerbate or attenuate the impact of the disease on the child (Ostroff, Ross, & Steinglass, 2000; Stuber, 1996). Moreover, because parents are often used as proxies to assess the quality of life and functioning of the child, their perceptions, functioning, and adjustment need to be considered.

Historically, findings from the caregiver literature on parents' adjustment to a child's cancer diagnosis are equivocal, with some studies revealing generally good parent adjustment (Frank, Brown, Blount, & Bunke, 2001; Kazak

& Meadows, 1989) and others indicating high rates of significant distress (Sloper, 2000; van Dongen-Melman et al., 1995; see Vannatta & Gerhardt, 2003 for a review). Some researchers have posited that these discrepant findings may reflect, at least in part, the method by which adjustment is assessed and a reliance on tools less sensitive to the experiences of parenting a child with a life-threatening illness (Eiser, 1998; Streisand, Braniecki, Tercyak, & Kazak, 2001). As such, in recent years, researchers have begun to focus on aspects of adjustment specific to the illness experience (Rodrigue, Geffken, & Streisand, 1999). Measures have focused on important domains such as impact on family (Stein & Reissman, 1980), aspects of illness-related functioning (Streisand et al., 2001), posttraumatic stress (Barakat et al., 1997; Brown, Madan-Swain, & Lambert, 2003; Kazak, Alderfer et al., 2004; Kazak, Stuber, Barakat, & Meeske, 1996; Manne, Du Hamel, Galleli, Sorgen, & Redd, 1998), maternal worry (DeVet & Ireys, 1998), and parental beliefs (Kazak, McClure et al., 2004).

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In addition to these important variables, recent literature suggests that subjective parent distress is an important factor in child outcomes. Specifically, Thompson and colleagues (Thompson & Gustafson, 1996; Thompson, Gustafson, George, & Spock, 1994) have proposed a model in which maternal adaptation processes contribute to child adjustment. In this model, maternal cognitive and emotional processes, as well as biomedical and other environmental factors interact in a transactional manner with child physical and emotional outcomes. Relevant to this model are specific aspects of parent adjustment that may be particularly salient in a chronic illness situation but have yet to be incorporated into quantitative measures that pertain to the entire illness trajectory. Two areas that have received little focus in recently developed quantitative measures include the concepts of illness-related uncertainty (Mishel, 1981; Stewart & Mishel, 2000) and chronic sorrow (Burke, Hainsworth, Eakes, & Lindgren, 1992; Eakes, Burke, & Hainsworth, 1998).

The construct of uncertainty has been discussed over the course of the past two decades by Mishel (1981, 1988, 1999), Koocher (Koocher & O'Malley, 1981; Koocher, 1984) and others (Cohen & Martinson, 1988; Cohen, 1995; van Dongen-Melman et al., 1995). Broadly defined, uncertainty pertains to both acute and ongoing or pervasive fear of possible illness consequences (e.g., death, recurrence, treatment-related sequelae; Stewart & Mishel, 2000). A recent review of the literature of parental uncertainty by Stewart & Mishel (2000) included 34 studies covering a wide variety of chronic illnesses. Although most of the cited studies were qualitative or descriptive, the review highlights the relationship between uncertainty and psychological distress (characterized by anxiety, depression, cognitive disturbances, and feelings of helplessness). Moreover, Mishel's (1981) uncertainty measure, the Uncertainty in Illness Scale, was modified for use with parents of hospitalized children (Parents' Perception of Uncertainty Scale, PPUS; Mishel, 1983). However, as noted by Stewart & Mishel (2000), because the PPUS was developed in the context of acute hospitalization, its validity for parents of children with chronic childhood illness has not been established. However, the accumulated findings from the extant literature suggest that parental uncertainty is critical construct to measure, given its theoretical and empirical relevance to child adjustment.

Parent adjustment may also reflect the experiences of and responses to ongoing loss. The accumulated findings from the literature demonstrate that parents of children with intellectual and/or developmental disabilities

as well as parents of children in specific illness contexts suffer long-term periodic sadness (Burke et al., 1992). Parents describe prolonged feelings of grief, disappointment, and fear in response to continual losses experienced over the trajectory of an illness or disability. Termed "chronic sorrow," this phenomenon has been described in adult patients (Hainsworth, Eakes, & Burke, 1994) as well as parents of children with mental handicaps (Krafft & Krafft, 1998; Wikler, Wasow, & Hatfield, 1981) and other chronic physical illness (cf. Northington, 2000). This sorrow reaction is considered a normal reaction to a complicated, though difficult situation, and thus is distinguished from clinical depression or pathological grief. Unfortunately, however, quantitative measures currently available to evaluate grief and sorrow are most relevant to end-of-life issues and are often administered retrospectively (Murphy et al., 1999; Zisook, Devaul, & Click, 1982). Moreover, other existing measures are qualitative, clinician-administered tools that have less practical utility for clinical and research purposes. As such, there is a need for a quantitative tool to assess this construct in parents of children with chronic illness.

Finally, assessment of perceived Emotional Resources is also important to the understanding of parental adjustment to chronic illness. Conceptualized as resistance factors by Wallander, Varni and colleagues (Wallander, Varni, Babani, Banis, & Wilcox, 1989), such variables may serve as indicators of adaptational resources in the face of a chronic stressor. Although coping strategies and behaviors have been well studied, cognitive appraisals of internal resources and perceived self-efficacy are also critical variables in a chronic illness population. Indeed, Kazak and colleagues (Kazak, McClure et al., 2004) recently found in their sample of parents of children with cancer, that perceived self-efficacy was related to parents' reports of adaptive family functioning, particularly for mothers. Given evidence relating cognitive resistance factors to psychosocial outcomes in the chronic illness population, there is a need for a valid, quantitative measurement tool to assess emotional resources across the illness trajectory.

In sum, these findings point to the need for new measurement tools to more comprehensively quantify illness-related issues and Emotional Resources of parents of children with chronic illness, particularly those pertaining to aspects of subjective distress such as chronic sorrow and uncertainty. Therefore, a new measure, the Parent Experience of Child Illness (PECI), was developed to measure important aspects of parent

adjustment. Assessment of the reliability and validity of the measure forms the basis of the current project.

## Method

### Participants

Consenting participants included 202 primary caregivers of pediatric patients (aged less than 1 year through 17 years) diagnosed with a brain tumor and followed through a medical center located in the Southeast. Participants included 157 mothers (77.7%), 38 fathers (18.8%), and 7 grandmothers (3.5%). Questionnaire packets were obtained from 149 (73.8%) of consenting participants. This return rate is above other published studies using a survey method where the response rate is closer to 55–60% (Baruch, 1999; Rosoff et al., in press). Compared with those who did not return a questionnaire packet, participants who did return a completed packet were significantly older ( $t = 3.18, p < .01$ ) and were more likely to have attended at least some college ( $\chi^2 = 13.5, p < .001$ ). The two groups did not, however, differ on other parent characteristics (i.e., gender, race) or on child demographics (i.e., age, gender, treatment status, age at diagnosis, months since diagnosis).

The final set of participants included 123 female caregivers (82.6%) and 26 male caregivers (17.4%). Most of the participants described themselves as Caucasian (81.9%,  $n = 122$ ), with other parents identifying as African American (16.1%,  $n = 24$ ) and Hispanic/Latino (2.0%,  $n = 3$ ). The average age of participants was 39.5 years ( $SD = 5.9$ , range = 18–52). Most of the sample had completed some college at the time of the study ( $n = 110, 73.8%$ ).

Pediatric patients ranged in age from 10 months to 18 years, with a mean age of 9.4 years ( $SD = 5.26$ ); slightly over half of the children were male ( $n = 78, 52.3%$ ). Time since diagnosis ranged considerably from less than 1 month to 15 years ( $M = 25.67$  months,  $SD = 35.459$ ); patients averaged 7.38 years of age ( $SD = 5.243$ , range = 2 months to 16 years) at time of diagnosis. Eighty-five (57.1%) children were considered on-treatment (i.e., actively receiving chemotherapy and/or radiation) at the time of the study. Children were described as “off-treatment” if they had completed treatment at least 2 months before study participation and were considered to be in disease remission. Tumor diagnoses were varied; approximately one-quarter of the sample ( $n = 38$ ) was diagnosed with medulloblastoma and 17.4% ( $n = 26$ ) was diagnosed with pilocytic astrocytoma. The remaining children were diagnosed with optic nerve glioma, ependymoma, glioblastoma multiforme, brain stem glioma, or other tumor types. Child demographic data are summarized in Table I.

**Table I.** Child Demographics

	<i>n</i> (%)	<i>M</i> ± <i>SD</i>
Age		9.4 ± 5.26
Gender		
Female	71 (47.7)	—
Male	78 (52.3)	—
Diagnosis		
Medulloblastoma	38 (25.5)	—
Pilocytic astrocytoma	26 (17.4)	—
Optic nerve glioma	21 (14.1)	—
Ependymoma	13 (8.7)	—
GBM	13 (8.7)	—
Brain stem glioma	8 (5.4)	—
Other	30 (20.1)	—
Age at diagnosis		7.4 ± 5.24
Months since diagnosis		25.7 ± 35.46
Treatment status		
On	85 (57.1)	—
Off	64 (42.9)	—

## Procedure

### Development of the Measure

The PEI was developed within the Divisions of Pediatric Neuro-Oncology and Pediatric Hematology-Oncology at a medical center in the Southeast. In the initial phase of development, a multidisciplinary team was composed to generate a preliminary list of items reflecting our clinical impressions of issues relevant to parenting a child with chronic illness. Team members included two pediatric psychologists, an oncology nurse practitioner, a social worker, a chaplain, and a pediatric neuro-oncologist. Although experience with a pediatric oncology population informed the item set, the final items were written so as to be applicable to other chronic illnesses.

This phase of development resulted in a 60-item measure that included questions covering theoretical domains derived from the literature, with primary emphasis on items pertaining to constructs of *Chronic Sorrow*, *Uncertainty*, and *Emotional Resources*. Some items relevant to parenting and personal distress that did not easily fall into these three domains, but were regarded as clinically salient issues, were also initially included. Further discussion among team members resulted in the elimination of 24 items due to redundancy with other items, ambiguous wording, and/or low relevance to theoretical constructs of interest. In total, team members met approximately 5 times over the course of 2 months to establish the initial item set.

The remaining 36 items were submitted to a small sample of parents of children diagnosed with cancer for review. The sample consisted of six parents (five mothers, one father): three parents of pediatric patients currently undergoing treatment for cancer and three parents of pediatric cancer survivors. Parents reported that the measure was easy to read and the directions were clear. However, on the basis of qualitative feedback provided by these parents, the measure was further reduced by 11 items. Specifically, several of the parents reported confusion in the wording of two items, which were subsequently dropped from the item set. Because the aim was to develop a measure that would be both germane to the experience of parents whose children have been diagnosed with a chronic illness and would be relevant to all stages of the illness, particular attention was paid to parents' comments on these issues. As such, eight additional items were dropped given parents' feedback that the items were (1) not specific to the chronic illness experience (one item), (2) were not likely to elicit variable responses among parents (three items), or (3) were not applicable to parents of survivors (four items). Thus, the current study addressed the psychometric properties of a 25-item version that included items pertaining only to illness-related items describing difficulties with *Chronic Sorrow*, *Uncertainty*, and *Subjective Parenting Distress*, as well as *Emotional Resources*. The final version, administered as a self-report, paper-and-pencil measure, was written at approximately the 4th grade reading level. Parents were given the following description and instructions: "This questionnaire is concerned with thoughts and feelings related to parenting a child who is living with, or who has experienced, a chronic illness. Read each statement and then try to determine how well it describes your thoughts and feelings over the past month."

Each item was rated on a five-point Likert-type scale as follows: 0, "Never"; 1, "Rarely"; 2, "Sometimes"; 3, "Often"; and 4, "Always."

### Data Collection

Following Institutional Review Board (IRB) approval, participants were recruited from a convenience sample of parents of pediatric patients who had been diagnosed with a brain tumor and were receiving medical care through the Division of Pediatric Neuro-Oncology at a medical center in the Southeast. Parents of children at all stages of the illness spectrum were invited to participate (e.g., diagnosis, active treatment, off-treatment, relapse). Only non-English-speaking persons were excluded.

Parents were approached by the project coordinator during one of their child's regular clinic visits to

assess their interest in participating in the study. When two or more caregivers were identified in a single family, participants were asked to determine the parent who assumed most of the illness-related care (e.g., accompanying child to clinic appointments, communicating with medical personnel, caring for the child's illness-related needs at home, etc.). Interested participants gave informed consent using IRB-approved methods. All participants approached ( $n = 204$ ) except two agreed to participate, for a consent rate of 99.0%. The two parents who declined participation cited busy schedules that prevented them from completing the questionnaires. Participants were asked to complete a demographics form while in the clinic, and then were provided with a packet of questionnaires to complete at home, approximately 1 week after the clinic visit. This was done in order to avoid acute inflation of distress associated with the clinic visit. Instructions for each questionnaire were reviewed with participants in the clinic and they were given a telephone number to call with questions. One week following their consent, parents were given a reminder call to fill out and return the questionnaire packet. After completion of the questionnaires, participants returned them to the research team by mail in a prepaid envelope.

Follow-up telephone calls were made to the 53 (26.2%) consenting participants from whom packets were not received in order to track nonrandom sources of response bias besides demographics. Twenty-four participants were never successfully contacted by telephone (i.e., did not return calls, telephone was disconnected, etc.), seven stated that they had indeed completed and mailed packets (which were never received by the research team), and four said that they had lost the questionnaire packets before having a chance to complete them. In addition, 15 said they were no longer interested in participating because they felt too busy. Finally, three participants said that they had started to fill out the questionnaire packets, but found the questions too distressing to complete. Of note, although these three parents had children who currently were undergoing active treatment, they differed on other variables including tumor type and age.

### Measures

#### Caregiver Strain Questionnaire

The Caregiver Strain Questionnaire, (CGSQ; Brannan, Heflinger, & Craig, 1997) developed for use in the Fort Bragg Evaluation Project (Bickman et al. 1995) is a 21-item self-report measure that assesses adults' perceptions of difficulties associated with their parenting role.

Factor analysis derived three subscales, Objective Burden, Externalized Subjective Burden, and Internalized Subjective Burden, all of which were used in the current study. Internal consistency reliability ranged from .74 to .93; evidence for construct validity with other measures of family and parental functioning has also been demonstrated (Brannan & Heflinger, 1997).

#### **Impact on Family Scale**

The Impact on Family Scale (IFS; Stein & Riessman, 1980; Stein & Jessop, 2003). is a widely used 33-item self-report measure designed to assess how current family functioning is affected by an illness. Subscales derived from factor analysis include economic burden, family/social impact, personal strain, and mastery; however, only the Total scale score (internal consistency reliability = .88; Stein & Riessman, 1980) was used in the current study. This measure demonstrates good psychometric properties as described by Stein & Jessop (2003).

#### **Brief Symptom Inventory**

The Brief Symptom Inventory (BSI; Derogatis & Spencer, 1982) is a 53-item self-report inventory for adolescents and adults designed to reflect a broad array of psychological symptom patterns. It includes nine symptom dimensions (somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism), though only the depression, anxiety, and global severity index (GSI) were employed in the current study. The BSI has demonstrated good test-retest reliability and construct validity (Derogatis, 1993), and has been used in research with chronic illness populations (see Thompson & Gustafson, 1996).

#### **Impact of Event Scale**

Impact of Event Scale (IES; Horowitz, Wilner, & Alvarez, 1979). The IES is a 15-item questionnaire rated on a four-point scale for frequency of Post Traumatic Stress Disorder symptoms during the previous week. The IES has high internal consistency and test-retest reliability (Zilberg, Weiss, & Horowitz, 1982) and has been used with childhood cancer survivors (Kazak et al., 1997; Kazak, Simms et al., 1999) as well as children with other medical conditions.

## **Results**

### **Exploratory Factor Analysis**

The 25-item version of the PEGI was submitted to an Exploratory factor analysis (EFA), by using data from

148 participants (one participant returned a PEGI that was missing a page). Of these 148 participants, missing items accounted for less than .4% of the set and appeared random; as such, mean substitution was used to fill in missing data. Because the primary aim of this analysis was to probe the latent factor structure, principal axis factoring with iterated communalities method of extraction was used (Fabrigar, Wegener, MacCallum, & Strahan, 1999). As the theoretical factors were assumed to be intercorrelated, an oblique method of rotation was selected (i.e., Promax with Kaiser Normalization; Fabrigar et al., 1999).

By using the Kaiser criterion and inspection of the scree plot, five factors were initially extracted, which collectively accounted for 60.8% of the variance. Due to significant cross-loadings and small numbers of items on some factors, four- and six-factor solutions were also extracted. As the four-factor solution contained fewer significant cross-loadings, this solution, which accounted for 56.5% of the total variance, was retained for further analysis. Broadly speaking, the pattern matrix contained moderate to large loadings on each factor with few cross-loadings. Specifically, loadings for each factor ranged from .38 to .87. Three items loaded modestly on two factors; in each case, the item was retained on two different factors for further analysis involving internal reliability and construct validity.

On the basis of the items contained in each factor, the four factors were named *Guilt and Worry* (11 items), *Unresolved Sorrow and Anger* (8 items), *Long-term Uncertainty* (5 items), and *Emotional Resources* (5 items). The first factor, *Guilt and Worry*, consisted of items pertaining to parents' concerns about their children's current and future well-being (e.g., I worry that my child's illness will worsen/return; I wake up during the night and check on my child.) as well as personal guilt (e.g., I worry that I may be responsible for my child's illness in some way.). The *Unresolved Sorrow and Anger* factor was comprised of items related to feelings of grief and anger over having to experience the chronic illness of a child (e.g., I am jealous of parents who have healthy children; I find it hard to socialize with people who don't understand what being a parent to my child means.). The third factor, termed *Long-term Uncertainty*, contained items describing both parents' sorrow about what paths their children's lives might have taken had they not become ill, as well as concerns about what their children's lives might be like in the future (e.g., My hopes and dreams for my child's future are uncertain.) Finally, the fourth factor contained items describing parents' perceived *Emotional Resources*, including parents'

feelings of competence and self-efficacy (e.g., I feel ready to face challenges related to my child's well-being in the future).

The items associated with each factor are listed in Table II along with the corresponding factor loadings, eigenvalues, and percent of variance explained. For subsequent analyses, scores for each factor were calculated by adding the item responses and dividing by the number of items on each factor (see Table III for scale descriptives). Of note, two items assessing Emotional Resources that cross-loaded negatively onto two distress factors were recoded so that higher scores reflected fewer perceived Emotional Resources.

As anticipated, the four factors were intercorrelated. Specifically, the three factors dealing with illness-related distress were moderately and positively intercorrelated ( $r$  ranged from .63 through .74; see Table IV), whereas the Emotional Resources factor evidenced a modest negative correlation with each of the distress factors ( $r$  ranged from  $-.37$  through  $-.51$ ; Table IV).

### **Internal Consistency**

To determine internal reliability within each factor, Cronbach's  $\alpha$  was computed for each of the four scales. As may be seen in Table III, reliability was adequate for each scale, ranging from .72–.89. Because internal reliability did not significantly improve with deletion of any items, all items were retained on each factor for subsequent analyses.

### **Construct Validity**

To evaluate construct validity, the four scales from the PECEI were compared with scores obtained from the BSI, Caregiver Strain Questionnaire (CGSQ), the IES, and the IFS using Pearson product-moment correlations. Given the large number of analyses, the alpha level was adjusted for each set of correlations using the conservative Bonferroni adjustment to control family-wise error rate. As a result, a  $p$  value less than or equal to .004 was used for correlations between PECEI scales and those of the subscales used from the BSI, CGSQ, and IES, and a  $p$  value of less than or equal to .013 was used for correlations between PECEI scores and the single score from the IFS.

As displayed in Table V, the PECEI scales correlated significantly with many of these scales. With regard to the PECEI distress scales, correlations with the established measures were generally moderate and positive, whereas correlations between the Emotional Resources scale and the established measures were uniformly negative and generally nonsignificant.

For the BSI, the Guilt and Worry scale was significantly and positively correlated with the Anxiety scale ( $r = .36, p < .004$ ), the Depression scale ( $r = .37, p < .004$ ), and GSI ( $r = .34, p < .004$ ). In addition, the Emotional Resources scale was significantly and negatively associated with the GSI ( $r = -.33, p < .004$ ). Finally, the Unresolved Sorrow and Anger scale was positively correlated with the BSI Depression subscale ( $r = .39, p < .004$ ) and the GSI ( $r = .34, p < .004$ ).

When comparing PECEI scales with the three subscales of the CGSQ, all three PECEI distress scales correlated significantly with the Internalized Subjective Burden scale (Table V). In addition, the Unresolved Sorrow and Anger scale from the PECEI was significantly and positively associated with the Objective Burden ( $r = .37, p < .004$ ) and Externalized Subjective Burden scales ( $r = .36, p < .004$ ).

Regarding the IES, the PECEI distress scales, but not the Emotional Resources scale, were significantly correlated with the IES Intrusion scale (Table V). The Unresolved Sorrow and Anger scale also was significantly associated with the IES Total scale ( $r = .50, p < .008$ ). In addition, the Guilt and Worry scale was positively correlated with the IES Avoidance subscale ( $r = .39, p < .004$ ) and the IES Total scale ( $r = .52, p < .008$ ).

Finally, examination of the associations between the PECEI scales and the summary score from the IFS revealed significant correlations with all three PECEI distress scales (Table V).

### **Parent and Child Characteristics**

To determine whether PECEI scores varied with parent or child demographic variables, scale scores were first submitted to a series of Hotelling's Trace analyses. This procedure was chosen over univariate  $t$ -tests to preserve power given the significant correlation between scale scores. The set of PECEI scale scores did not significantly vary with parent gender, race, or educational status. Moreover, PECEI scale scores also were not significantly associated with child gender, race, or diagnosis, but did vary as a set with child treatment status. Specifically, although the multivariate model supported a pattern of significant differences between parents of on- and off-therapy children (Hotelling's  $T = .08, F = 2.83, p < .05$ ), further comparison of the two groups on individual scales was nonsignificant (Table VI). Finally, the continuous demographic variables of parent age, child age, age at diagnosis, and months since diagnosis were compared with the PECEI scale scores using Pearson product-moment correlations; no significant associations were found.

**Table II.** Summary of Exploratory Factor Analysis Results for the PECl Using Principal Axis Factoring with Promax Rotation ( $n = 148$ )

Item	Factor 1	Factor 2	Factor 3	Factor 4
	Guilt and Worry	Unresolved Sorrow and Anger	Long-term Uncertainty	Emotional Resources
I worry that any minute, things might take a turn for the worse.	.46	.18	.16	.03
I think about whether or not my child will die.	.52	.06	.27	.01
I am afraid of this diagnosis occurring in another member of my family.	.75	-.17	-.15	-.19
I worry that my child's illness will worsen/return.	.48	.05	.26	.08
I feel guilty because my child became ill, whereas I remained healthy.	.71	-.13	.11	-.11
I worry that I may be responsible for my child's illness in some way.	.73	-.20	.05	-.17
I worry about something bad happening to my child when s/he is out of my care.	.50	.31	-.03	.15
When my child is actively playing, I find myself worried that s/he will get hurt.	.59	.06	.03	.12
I wake up during the night and check on my child.	.40	.28	.03	.22
When I'm not with my child, I find myself thinking about whether or not s/he is ok.	.55	.48	-.27	.22
I trust myself to manage the future, whatever happens.	-.47	.03	.05	.64
I feel ready to face challenges related to my child's well-being in the future.	.15	-.17	-.07	.68
I can get help and support when I need it.	-.01	-.25	-.02	.43
I am aware of the specific ways I react to sadness and loss.	.01	.05	.01	.40
I am at peace with the circumstances in my life.	-.07	-.52	.05	.38
I experience angry feelings when I think about my child's illness.	.23	.45	.04	-.08
I find it hard to socialize with people who do not understand what being a parent to my child means.	.12	.54	.04	-.05
I believe I will never be as completely happy or satisfied as I was before my child became ill.	.00	.54	.24	-.17
I am jealous of parents who have healthy children.	-.15	.87	-.09	-.11
Seeing healthy children doing everyday activities makes me feel sad.	-.14	.82	-.09	-.03
It is painful for me to think about what my child might have been like had s/he never gotten sick.	-.06	.43	.45	-.04
I have regrets about decisions I have made concerning my child's illness.	.09	-.13	.52	-.12
My hopes and dreams for my child's future are uncertain.	-.12	.07	.86	.02
I worry about my child's future.	.19	.10	.53	.17
I worry about whether my child will be able to live independently as an adult.	.04	-.17	.73	-.02
Eigenvalues	9.01	2.14	1.56	1.41
Percent of variance	36.06	8.54	6.23	5.62

Loadings in bold face represent items included on each factor.

**Table III.** Descriptive Statistics and Internal Consistency of the Parent Experience of Child Illness (PECI) Scales

Subscale	$\alpha$	Minimum	Maximum	<i>M</i>	<i>SD</i>	25th percentile	75th percentile
Guilt and Worry	.89	.00	3.82	1.72	.773	1.09	2.27
Emotional Resources	.72	.80	4.00	2.70	.658	2.20	3.20
Unresolved Sorrow and Anger	.86	.00	3.63	1.51	.820	0.88	2.13
Long-term Uncertainty	.80	.00	4.00	1.97	.867	1.40	2.60

Scores are based on items that ranged from 0, "Never" to 4, "Always."

**Table IV.** Pearson Correlations Between Parent Experience of Child Illness Scales

Subscale	Long-term Uncertainty	Unresolved Sorrow and Anger	Emotional Resources
Guilt and Worry	.63*	.74*	-.40*
Emotional Resources	-.37*	-.51*	—
Unresolved Sorrow and Anger	—	.67*	—

\* $p < .01$ .

## Discussion

The current study provides initial psychometric data on the PEGI, a new measure developed to assess important domains of subjective distress experienced by parents of children with a chronic illness. By using theoretically derived items generated by a multidisciplinary team and modified by parent feedback, a 25-item measure was developed and evaluated in a pediatric neuro-oncology sample. The measure was designed to assess constructs of caregiver uncertainty, chronic sorrow, general subjective distress, and perceived emotional resources. An EFA of the measure yielded four factors, including, *Guilt*

and *Worry*, *Unresolved Sorrow and Anger*, *Long-term Uncertainty*, and *Emotional Resources*. Factors were renamed postanalysis to better capture content on each scale. These factors demonstrated adequate internal consistency and also correlated significantly with several established measures of parent adjustment. Thus, this study provides preliminary evidence of the reliability and validity of this new measure for use in a pediatric brain tumor population.

In addition to establishing the psychometric properties of the measure, results of the study have several important implications. First, the PEGI augments the current literature by providing a brief measure that assesses critical domains of parent adjustment that have been largely omitted from both global measures of psychopathology and illness-related measures frequently used in this population. Compared with other recent illness-specific measures for parents, the PEGI focuses more specifically on aspects of subjective distress and perceived emotional resources. As such, the PEGI provides data on parent adjustment that may be of both clinical and research utility. For example, the Guilt and Worry factor appears to tap parents' apprehension about parenting and making decisions for a seriously ill child.

**Table V.** Pearson Correlations Between Parent Experience of Child Illness (PECI) Scales and Scales from the Brief Symptom Inventory (BSI), Caregiver Strain Questionnaire (CGSQ), Impact of Event Scale (IES), and Impact on Family Scale (IFS)

Scale	Unresolved Sorrow and Anger	Guilt and Worry	Long-term Uncertainty	Emotional Resources
BSI				
Anxiety	.32	.36*	.15	-.30
Depression	.39*	.37*	.17	-.32
Global severity index	.34*	.19	-.33*	—
CGSQ				
Objective Burden	.37*	.30	.18	-.15
Internalized Subjective Burden	.57**	.60**	.46*	-.30
Externalized Subjective Burden	.36*	.24	.19	-.22
IES				
Intrusion	.59****	.51****	.33***	-.22
Avoidance	.28	.39***	.12	-.25
Total	.50**	.26	-.27	—
IFS total	.44****	.38****	.31***	-.05

\* $p < .004$ . \*\* $p = .008$ . \*\*\* $p < .013$ . \*\*\*\* $p = .003$ .



**Table VI.** Analysis Results for Children's Treatment Status and Parent Experience of Child Illness (PECI) Scales

Scale	On treatment	Off treatment	<i>p</i>
	<i>M</i> ± <i>SE</i>	<i>M</i> ± <i>SE</i>	
Guilt and Worry	1.78 ± .084	1.64 ± .097	1.20
Unresolved Sorrow and Anger	1.53 ± .089	1.49 ± .104	.07
Emotional Resources	2.78 ± .071	2.61 ± .083	2.08
Long-term Uncertainty	1.90 ± .094	2.08 ± .109	1.57

Multivariate model was significant ( $T^2 = .08$ ,  $F = 2.83$ ,  $p < .05$ ); all univariate comparisons were nonsignificant.

Parents scoring high on this factor may acutely feel a burden of responsibility (e.g., deciding to start or end treatment, managing physical symptoms or crises, etc.) that transcends the typical caregiver role. These parents may see their child as fragile and manifest anxiety about whether they will be able to effectively manage problems associated with their child's vulnerability. With regard to theoretical constructs, this factor appears to contain several features of uncertainty as described in the literature (e.g., Cohen, 1995; Koocher & O'Malley, 1981; Mishel, 1981). Specifically, the factor includes items that assess fears and worries about prognosis, treatment decisions, and disease etiology; all are features of uncertainty, especially in the *acute* context. It is important to note that uncertainty in this respect may be distinguished from additional features of the concept that appear in the Long-term Uncertainty factor, discussed below. Of the three "distress" factors identified in the PEGI, the Guilt and Worry factor appears to deal most with acute anxiety. Perhaps for this reason, this scale was associated with several indicators of general and posttraumatic stress as measured by the BSI and IES subscales. In addition, the Guilt and Worry factor also was positively correlated with perceived impact on family and parenting worries.

Related to the Guilt and Worry factor was Factor 3, Long-term Uncertainty. This factor appears to describe ruminative concern about children's future well-being, as well as implications of past decisions or events on the child's long-term health and success. In this way, the factor closely resembles features of the uncertainty construct as described by Mishel, (1981), particularly in a future-oriented context. Of interest, in contrast to the acute anxiety tapped by the Guilt and Worry factor, the Long-term Uncertainty factor does not appear to be related to indices of psychopathology or parenting distress. Indeed, the Long-term Uncertainty factor evidenced low to modest correlations with established measures of parent adjustment and distress. As such, Long-term Uncertainty may represent a unique aspect of

parent adjustment not included in other measures. This result, if replicated in future studies, may have implications for clinical practice. Parents with high levels of long-term uncertainty may not be referred for traditional interventions (e.g., psychiatric care), but may benefit from other forms of supportive therapy.

Of the three factors dealing with parent distress, the Unresolved Sorrow and Anger scale appears most related to the construct of chronic sorrow as described by Burke and colleagues (Burke et al., 1992). Parents who score highly on this scale may feel a sense of ongoing loss associated with their child's illness, regardless of whether or not their child has experienced treatment success or remission. In particular, these parents may experience feelings of grief and anger about the loss of their medically, psychologically, and/or neurocognitively healthy child, and the perceived loss of the happier, easier, or more "normal" course their own lives may have taken but for the illness. It is interesting that higher scores on this scale were robustly associated with higher scores on the IES Intrusion subscale as well as the Internal Subjective Burden scale from the CGSQ. This suggests that parents reporting higher levels of Unresolved Sorrow and Anger are also experiencing higher levels of intrusive thoughts about and emotional strain caused by their child's illness. Moreover, higher scores on this factor also were modestly associated with higher BSI Depression and GSI scores as well as higher IFS Total Scale scores. As such, parents with high Unresolved Sorrow and Anger may evidence less adaptive functioning that, in turn, may impact child adjustment (Thompson & Gustafson, 1996).

Whereas the first three factors in the PEGI highlight parents' perceptions of negativity associated with the illness experience, the fourth factor, Emotional Resources, is associated with parents' perceptions of their positive inner resources. Of importance, *all* parents in our sample endorsed at least some perceived resources, and most parents reported moderate levels of self-efficacy and confidence in their ability to manage current and future challenges related to their child's well-being. Moreover, higher scores on the Emotional Resources scales were associated with lower reported general distress as measured by the BSI. This finding is in keeping with theoretical models and evidence of the importance of resistance factors such as healthy cognitive appraisals in parent's and child's adaptation to chronic illness (e.g., Wallander et al., 1989).

With regard to limitations of this study, we administered the PEGI to a group of parents within one illness population. Patients with brain tumors represent a distinct population in terms of treatment, mortality, morbidity,

and long-term physical and psychosocial sequelae. Indeed, this may be one reason why a robust pattern of differences between the PECEI scores of parents of on- and off-treatment patients was not found. As such, generalizability to non-neuro-oncology populations, while within the theoretical scope of the measure, is unclear and a question for future research studies. Towards this aim, data are currently being collected to validate this measure in pediatric patients with other cancers and with other scales designed for pediatric patients (e.g., PIP; Streisand et al., 2001).

Other limitations in the study stem from sampling issues. For example, some parents in this sample were missed in nonrandom ways. Specifically, younger, less educated parents were less likely to return the measures, many of who cited their busy schedules as the reason for not completing the study. It is unknown whether parents in this group were more or less distressed than the rest of the sample. Moreover, three parents reported that the measures were too distressing to complete; as such it is possible that our sample may have missed some of those parents who exhibit the poorest adjustment. Additionally, for the purposes of this study, we identified the primary caregiver as the person who assumed the majority of the illness-related care. As a result, there were significantly more mothers than fathers who participated. Considered together, these results indicate a need for subsequent validation studies that specifically target younger parents, fathers, and additional illness populations. Additionally, all data collected were based on subjective parent report. Evaluation of parent adjustment from other sources (e.g., physician, social worker) will provide additional information about the utility and validity of the PECEI. Finally, future studies should consider other factors that may be related to parent adjustment including prognosis, treatment type, and stage of illness (e.g., diagnosis, relapse, end-of-life, survivorship).

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