

Outcome Measure	Parent Experience of Child Illness (PECI)
Sensitivity to Change	Yes
Population	Paediatrics
Domain	Family Environment
Type of Measure	Parent-report
ICF-Code/s	E4
Description	<p>The Parent Experience of Child Illness (PECI) (Bonner et al. 2006) is a 25-item measure designed to examine parental adjustment related to caring for a chronically ill child (Bonner et al. 2006). The Peci comprises four subscales:</p> <ol style="list-style-type: none"> 1) Guilt and Worry, 2) Unresolved Sorrow and Anger, 3) Long-term Uncertainty, and 4) Emotional Resources. <p>Parents are given the following description and instructions prior to completing the questionnaire: "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."</p> <p>Each item is rated on a five-point Likert-type scale as follows: 0, "Never"; 1, "Rarely"; 2, "Sometimes"; 3, "Often"; and 4, "Always."</p>
Properties	<p>DEVELOPMENT</p> <p>The Peci was developed within the Divisions of Paediatric Neuro-Oncology and Paediatric Hematology-Oncology at a medical centre 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 paediatric psychologists, an oncology nurse practitioner, a social worker, a chaplain, and a paediatric neuro-oncologist. Although experience with a paediatric 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</p>

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). 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."

Sample items

- I worry that any minute, things might take a turn for the worse.
- I am afraid of this diagnosis occurring in another member of my family.
- I feel ready to face challenges related to my child's well-being in the future.
- Seeing healthy children doing everyday activities makes me feel sad.

	<ul style="list-style-type: none"> • I worry about whether my child will be able to live independently as an adult. <p>PSYCHOMETRIC PROPERTIES</p> <p>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.</p> <p>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.</p> <ol style="list-style-type: none"> 1) Exploratory factor analysis yielded four theoretically coherent factors including: Guilt and Worry, Emotional Resources, Unresolved Sorrow and Anger, and Long-term Uncertainty. 2) 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, suggesting adequate construct validity (Bonner et al. 2006). 3) No gender differences in scores are noted between mothers and fathers suggesting its validity for use in both (Bonner et al. 2007). 4) Cronbach’s alpha for the Guilt and Worry, Unresolved Sorrow and Anger, Long term Uncertainty, and Emotional Resources subscales in this sample were between .67 and .87.
Advantages	Could be useful for measuring treatment outcomes associated with parenting. It also measures impact of treatment.
Disadvantages	No normative data, as only relevant to chronic illness
Additional Information	-
Reviewers	Vicki Anderson Cathy Catroppa

References

Bonner, M. J., Hardy, K K., Guill, A. B., McLaughlin, C., Schweitzer, H., & Carter, K. (2006). Development and Validation of the Parent Experience of Child Illness. *Journal of Pediatric Psychology, 31*, 310-321.