Exploratory and Confirmatory Factor Analysis of the Child Uncertainty in Illness Scale Among Children with Chronic Illness

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Objective To conduct an exploratory factor analysis (EFA) and a confirmatory factor analysis (CFA) of the Child Uncertainty in Illness Scale (CUIS) with a sample of children and adolescents with a chronic health condition. Developmental differences in factor structure were also examined. **Methods** A sample of 373 children aged 8–18 years with chronic conditions completed the CUIS as a part of a larger battery of measures. **Results** The EFA yielded a 16-item two-factor model termed Unpredictability/Ambiguity and Comprehension. The CFA yielded a 14-item two-factor model that fits the data very well, where $\chi^2(df = 74) = 95.396$, Comparative Fit Index (CFI) = .973, Tucker Lewis Index (TLI) = .967, and Root Mean Square error of approximation (RMSEA) = .038. No developmental differences were found in underlying factor structures: $\Delta\chi^2(df = 12) = 17.754$, ΔCFI = .004, ΔTLI = –.001, and ΔRMSEA = .000. **Conclusions** The two-factor CUIS measure could be a useful tool for assessing illness uncertainty among children with chronic illness.

Key words Child Uncertainty in Illness Scale; childhood chronic condition; confirmatory factor analysis; exploratory factor analysis; illness uncertainty.

Illness uncertainty (IU) is defined as a cognitive experience elicited in situations in which the meaning of illness-related events is unclear and outcomes are unpredictable (Mishel, 1990). Mishel conceptualized the overarching construct of IU as being composed of distinct subcomponents, including ambiguity regarding the cues and the state of the illness, the unpredictability of illness course and outcomes, complexity regarding the treatment and the health care system, and the lack (or inconsistency) of information regarding the illness or treatments. The IU construct is often assessed in adult populations using the Mishel Uncertainty in Illness Scale (MUIS; Mishel, 1997). The availability of this standardized, self-report measure of perceived IU has facilitated an extensive literature demonstrating a robust association between IU and psychological distress during diagnosis, treatment, and stabilization periods of an illness (e.g., Mishel, 1984; Mishel & Braden, 1987), across a wide array of adult illness groups, including myocardial infarction (Bennett, 1993), multiple sclerosis (Mullins et al., 2001), and cancer (Mast, 1998; Mishel & Sorenson, 1991), among others. These findings suggest that the perceptions of IU may be a critical cognitive factor that can place individuals with chronic illness at increased risk of experiencing poor adaptation to their illness or clinically significant psychological distress.

Children and adolescents also experience IU concerning the symptoms and treatments of their condition, illness recurrence, as well as their ability to engage in daily activities (Greenberg & Meadows, 1991; Haase & Rostad, 1994). Mirroring the adult IU literature, studies demonstrate that increased IU is significantly associated with increased depressive symptoms (Hoff, Mullins,

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Chaney, & Hartman, 2003; White et al., 2005), anxiety (Hommel et al., 2003), and global distress (Mullins, Chaney, Pace, & Hartman, 1997) among children and adolescents with chronic health conditions. Child IU was also found to moderate the relationship between global parent distress and child-reported depressive symptoms among children with rheumatic disease (White et al., 2005). Collectively, these findings suggest that children with chronic conditions indeed experience IU and that uncertainty may be related to psychological distress or adjustment. However, most studies examining IU in children with chronic conditions have employed qualitative methods (Greenberg & Meadows, 1991; Haase & Rostad, 1994) or were conducted with samples of older adolescents using adult measures of IU (Hommel et al., 2003; Mullins et al., 1997; Neville, 1998).

Therefore, the purpose of this study is to evaluate the factor structure of a child IU measure—the Child Uncertainty in Illness Scale (CUIS; Mullins & Hartman, 1995) using an exploratory factor analysis (EFA) and a confirmatory factor analysis (CFA)—as well as to test for potential developmental differences in factor structures between children and adolescents. The CUIS is a modified version of the MUIS-Community Form (Mishel, 1997). In an attempt to provide a more developmentally appropriate measure of uncertainty for children, items were abbreviated and then edited to achieve no higher than a third-grade reading level for each item. The CUIS consists of 23 items that assess the child's perceived uncertainty about their own illness, including perceived ambiguity regarding the state of their condition, the unpredictability of the course, and the lack of information regarding their condition. Children respond on a 5-point Likert scale ranging from 1 (*very true*) to 5 (*very false*). In the previous studies, the CUIS demonstrated good internal consistency: .89 (Hoff et al., 2003) and .93 (White et al., 2005). Preliminary evidence for the validity of the CUIS has also been demonstrated by its significant association with depressive symptoms among children and adolescents with type 1 diabetes (Hoff et al., 2003) and juvenile rheumatic disease (White et al., 2005). However, to date, the factor structure of the CUIS has not been examined.

A standardized and psychometrically sound measure of the CUIS could facilitate future research examining changes in child IU over time, the relationship of IU to child and parent psychological distress, and whether IU is an important target for intervention. To our knowledge, there are no longitudinal studies with children and adolescents examining the directional relationship between self-reported IU and psychological distress. Such investigations are needed, as longitudinal studies among adults have demonstrated that higher IU is related to subsequent decreased mood and diminished hope among individuals with multiple sclerosis (Wineman, Schwetz, Zeller, & Cyphert, 2003) and distress following myocardial infarction (Christman et al., 1988). Notably, the influence of uncertainty on emotional responses to an illness persist well past the treatment phase of an illness. Using structural equation modeling, a recent study found that IU was related to mood state and troublesome illness-related thoughts among women 5–9 years after breast cancer treatment (Clayton, Mishel, & Belya, 2006). Parental uncertainty about their child's chronic illness has also been found to predict subsequent parental psychological distress 5–6 years later after controlling for initial levels of distress (Carpentier, Mullins, Chaney, & Wagner, in press). Furthermore, interventions designed to decrease IU lead to increased use of cognitive reframing and coping skills among breast cancer survivors (Mishel et al., 2005).

Therefore, the goals of the present study were threefold: (a) to conduct an EFA and a CFA of the CUIS in children with chronic illness conditions, (b) to determine whether there were developmental differences between children and adolescents in the factor structure of the CUIS, and (c) to determine whether the identified factors are associated with psychological distress, specifically depressive symptomotology. Both the EFA and CFA were conducted on individual items to construct each factor and to determine the degree to which each item cross-loaded on other factors. Because there are no studies that have examined potential developmental differences in perceptions of IU, we tested whether there were differences between children and adolescents in the factor structure of the CUIS. Finally, we examined whether IU was related to depressive symptoms.

Methods

Participants

A sample of 373 children and adolescents were recruited as part of four separate studies examining childhood chronic illness. Inclusion criteria were as follows for all studies: children were between 8 and 18 years of age and had been diagnosed with a chronic illness as identified by physician report or chart review. Exclusion criteria were identical for all studies: children who demonstrated evidence of significant cognitive deficits that would interfere with their ability to accurately complete the questionnaire and/or children that had a comorbid chronic illness were excluded. Mean age of the children was 12.64 (SD = 2.73). Fifty-one percent of the children

were boys. Racial composition of the sample was as follows: 71% Caucasian, 14% African American, 8% Native American, 2% Asian, 1% biracial, and 4% other. Estimated annual household incomes, obtained via self-report, were as follows: 0–9,999 (10%), 10,000–19,999 (9%), 20,000–29,999 (11%), 30,000–39,999 (13%), 40,000–49,999 (7%), 50,000–59,999 (17%), and >60,000 (33%). The chronic health conditions included type 1 diabetes (41%), asthma (20%), cystic fibrosis (11%), cancer (6%), sickle cell disease (7%), and juvenile rheumatic disease (15%). These diagnoses were chosen to provide a sample of a variety of chronic conditions representative of those seen by medical professionals in a wide range of pediatric settings.

Procedure

All participants completed the CUIS as a part of a larger battery of instruments in four independent studies examining cognitive mechanisms related to adaptation among children with chronic health conditions (Hoff et al., 2003; White et al., 2005). All studies had the institutional review board's approval and were conducted in accord with the ethical principles of the American Psychological Association. Informed consent was obtained from caregivers, and assent was obtained from the children. Potential participants were recruited through one of two methods: (a) participants received solicitation letters describing the study and a return postcard on which they indicated their willingness to participate and were mailed a protocol packet or (b) the study participants were approached in a specialty clinic, and those who agreed to participate completed the measures in the clinic. In total, 546 families agreed to participate in the studies. Recruitment rates for all four studies ranged from 44 to 80% for 373 completed and returned questionnaires. Seventy-six percent (n = 131) of those who did not complete the study cited the lack of time as the reason for not completing, and 24% (n = 42) were lost to follow-up. Parents of the children and adolescents were asked to complete questionnaires detailing demographic and illness information. A subsample of 237 children and adolescents also completed measures of depressive symptomatology. Participants were included in this subsample if they completed the same measure of depressive symptomatology as their respective age group. Participants who returned completed questionnaires were sent thank-you letters and $10 gift cards.

Measures

Demographic Information

Parents of the children provided demographic information via a questionnaire developed to obtain the following information: child's gender, child's age, child's race, child's diagnosis, and income.

Children's Uncertainty in Illness Scale (Mullins & Hartman, 1995). The CUIS is a 23-item self-report measure of the child's perceived IU about the course, prognosis, and treatment of their illness. The CUIS is an adapted version of the MUIS-Community Form (Mishel, 1997) that was revised to be developmentally appropriate for children and adolescents. See Table I for item content. Respondents are asked to respond on a 5-point scale ranging from 1 (*very true*) to 5 (*very false*). A CUIS total score of IU is obtained by summing across all items, with higher scores indicting greater levels of uncertainty.

Children's Depression Inventory (CDI; Kovacs, 1992). Children between 8 and 12 years of age completed the CDI that is a widely used 27-item self-report measure of depressive symptomatology. The respondent endorses one of three choices for each item. Each item includes such choices as "I am sad once in a while," "I am sad many times," and "I am sad all the time." Scores range from 0 to 51, with higher scores indicating higher levels of depression. Raw scores were converted to T scores based on a normative sample (Kovacs, 1992). Adequate internal consistency and test-retest reliability have been demonstrated (Smucker, Craighead, & Green, 1986), with coefficient αs ranging from .71 to .87.

Brief Symptom Inventory (BSI; Derogratis, 1993). A subsample of adolescents completed the BSI that assesses nine clinical dimensions of psychological distress. Respondents rate the perceived severity of various psychological and physical symptoms experienced during the previous 7 days on a 5-point scale ranging from 0 (*not at all*) to 4 (*extremely*). T scores for the depression subscale based on nonpatient adolescent norms were used as a measure of depressive symptomatology. The BSI has adequate internal consistency (.71–.85) and test-retest reliability (.68–.91).

Overview of Statistical Analyses

Analyses were conducted in four stages. The analytic strategies as employed in the current study are described in detail below.

Exploratory Factor Analysis. In the first stage, an EFA was conducted to identify a viable factor structure based on a randomized split of the data in the sample. A sample of 171 participants was randomly selected using the randomization function on SPSS 12.0. An EFA, using principal axis factor analysis, was then conducted on this subset of participants to determine the factor structure of the 23 items of the CUIS. Items with primary factor loadings ≥.40 (including values that

Table I. Items Retained in the Child Uncertainty in Illness Scale (CUIS) after the exploratory factor analysis (EFA) and the Respective Factor Loadings

Items	Factor 1	Factor 2
Unpredictability/Ambiguity		
15. I am not always sure what is going to happen to me	.741	−.103
13. I never know how I will feel, I have good days and bad days	.650	−.200
3. I don't know if my illness is getting better or worse	.648	.211
4. I don't know how bad my pain will be	.644	
14. Everybody seems to have different ideas about what is wrong with me	.622	−.105
11. It is hard to know if the treatments or medicine I am getting are helping me get better	.587	.197
12. Because I don't know what's going to happen with my illness, I cannot plan for the future	.569	.117
9. The doctors say things to me that could mean a lot of different things	.557	
7. I don't know why some days I feel worse	.532	.207
16. The results of my tests go back and forth between good and bad	.523	
2. I have a lot of questions about my illness and I don't know what the answers are	.465	.185
Comprehension		
22. I know how bad my illness is		.780
21. They have not told me what is wrong with me		.652
23. The doctors and nurses explain things so I can understand		.630
20. I know the treatment I am getting will work and make me better		.461
8. I understand everything they tell me about my illness	.165	.451

n = 171, loadings on factors <.100 were suppressed and therefore not presented in the table. Items removed from the measure based on the EFA were as follows: 1. I don't know what is wrong with me, 5. Things they tell me about my illness confuse me, 6. I don't know why I have to do each of the treatments, 10. My treatment is hard to figure out, 17. They do not know if the treatment will work, 18. Because of my treatment, I never know what I can and cannot do, and 19. I know they will not find anything else wrong with me. Items 8, 20, 22, and 23 are reverse scored.

rounded to .4) and secondary factor loadings ≤.30 and those that did not load on more than one factor were retained. Items not meeting these criteria were removed one at a time. Factor analyses were repeated until a solution in which all the items included in the analysis met all criteria was attained.

Confirmatory Factor Analysis. Using Analysis of Moment Structures (AMOS), Version 5.0 (AMOS 5.0; Arbuckle, 2003), a CFA was then conducted on the remaining 202 participants of the larger overall sample to determine whether the factor structure required modification. The CFA was used to confirm the exploratory model and, if possible, to refine the model using a separate sample of participants. CFA is a structural equation modeling technique used to determine the goodness of fit between a hypothesized model and the sample data. The determination of whether to add a path to a model is based on a combination of theoretical, logical, and empirical indications. Empirically, the examination of modification indices guided path additions to the model. Modification indices are suggestions made by AMOS for paths that can be entered into the model to improve the goodness-of-fit (Kline, 1998). If a modification index between two items is high in relation to other modification indices, it suggests that the addition of a path will improve the overall fit of the model. Theoretically, item content is examined. If, from a theoretical standpoint, these items are expected to be related to one another, then it is additional support for the inclusion of a path. If it does not make theoretical or logical sense, then the path should not be included. The following goodness-of-fit indices were used to assess the degree of fit between the model and the sample: χ^2, Tucker Lewis Index (TLI; >.90 acceptable, >.95 excellent; Tucker & Lewis, 1973), the Comparative Fit Index (CFI: >.90 acceptable, >.95 excellent; Bentler, 1990; Bentler & Bonett, 1980), and Root Mean Square error of approximation (RMSEA; <.08 acceptable, <.05 excellent; Brown & Cudeck, 1993). The CFA affords several advantages over other analytic techniques in that it allows the specification of causal relationships between observed variables and latent constructs while simultaneously accounting for item-level measurement error (Bryant & Yarnold, 1995).

Multigroup Comparison. A multigroup CFA was then conducted to identify potential developmental differences in factor structure. In a multigroup CFA, the pattern of factor loadings for the CUIS was tested for equivalence across each age group: 8–12 and 13–18 years. There are three primary steps in a multigroup CFA: (a) determining the factor structure of the measure across each group freely estimating the factor loadings (unconstrained model); (b) determining the factor structure of the measure across each group constraining the factor loadings to be equal (constrained model);

(c) comparing the goodness-of-fit indices between the constrained and unconstrained models. Differences between groups were assessed by comparing the goodness-of-fit indices of the model with factor loadings constrained to be equal to the unconstrained base model (Byrne, 2004). If significant differences are observed between the constrained and unconstrained model goodness-of-fit indices, this indicates variance across groups—in short, the factor structure is not same. If no significant differences are observed between the constrained and unconstrained model goodness-of-fit indices, this indicates invariance across groups—the factor structure is considered to be the same.

Relationship Between Uncertainty and Distress. To evaluate the relationship between the CUIS and depressive symptoms, we conducted correlational analyses on participants for whom the measures of depressive symptoms were available.

Results

Exploratory Factor Analysis

The EFA yielded a 16-item measure with a two-factor solution: 11 items measuring a factor called *Unpredictability/Ambiguity* and five items measuring a factor called *Comprehension*. Items 1, 5, 6, 10, 17, 18, and 19 were removed from the original 23-item measure. Each item was removed on the basis of predetermined criteria. Items were removed from the measure if they did not have primary factor loadings that were ≥.40 (including values that rounded to .4) and secondary factor loadings ≤.30 or if the item loaded on more than one factor. The individual items retained in the model and factor loadings are presented in Table 1. Each factor was then interpreted by examining item content and pattern of coefficients. Items loading on factor 1 (Unpredictability/Ambiguity) included content characterized by unpredictability of the condition course, including ambiguous and unpredictable symptomatology, as well as unpredictable treatment outcomes. Items loading on factor 2 (Comprehension) included content that reflected understanding the nature of the illness or the treatments. The internal consistency for each of these factors was estimated using Cronbach's (1951) coefficient α: for factor 1, $\alpha = .85$; and for factor 2, $\alpha = .76$.

Confirmatory Factor Analysis

The two-factor solution derived from the EFA was then cross-validated on 202 participants retained from the same overall sample on which the EFA was conducted. Figure 1 shows the final CFA for the sample. The initial model was then run and resulted in a poor fit. Item 13, "I never know how I will feel, I have good days and bad days," was removed because it cross-loaded on both factors (loading on Comprehension factor –.40 and on the Unpredictability/Ambiguity factor .62). Based on modification indices, a path of covariance was then added between error terms for items 11 and 15, resulting in an improved but still poor fitting model. Next, it was suggested by the modification indices that item 8 cross-loaded on the Unpredictability/Ambiguity factor. The examination of the factor loadings revealed that item 8 loaded weakly on both factors (loading on Comprehension factor .28 and on the Unpredictability/Ambiguity factor .29). Therefore, item 8, "I understand everything they tell me about my illness," was removed. The examination of the item content also revealed that the item was too broad, as it is unlikely that any child would understand "everything" about their illness. This resulted in an improved but inadequate model. Finally, a path of covariance was added between error terms for items 11 and 20. Although it is not customary to draw paths between error terms that load on two different factors, the path between items 11 (Unpredictability/Ambiguity) and 20 (Comprehension) was included. Both items contained content specifically regarding the outcomes of medical treatment (e.g., both items measure the degree to which the child perceives that the treatment is making them better), likely accounting for the high covariance between the error terms for each of the items. Fit indices for each of the models tested are presented in Table II. The final model shows an excellent fit to our data, where $\chi^2(df = 74) = 95.396$, CFI = .973, TLI = .967, and RMSEA = .038.

Multigroup Comparison

To determine whether the final model differed based on age of the child, the overall sample was split into two age groups: ages 8–12 and 13–18 years. A multigroup comparison was then conducted to determine whether the CUIS has the same theoretical structure for each age group. No significant differences between the constrained and unconstrained models were identified, indicating that the model is valid for children both in the younger and in the older age groups: $\Delta\chi^2(df = 12) = 17.754$, ΔCFI = .004, ΔTLI = –.001, and ΔRMSEA = .000. See Table II for detailed multigroup comparison fit indices.

Relationship of CUIS Factors to Child Distress

The Unpredictability/Ambiguity and Comprehension factors were then correlated with measures of depressive symptoms for the entire sample. The Unpredictability/

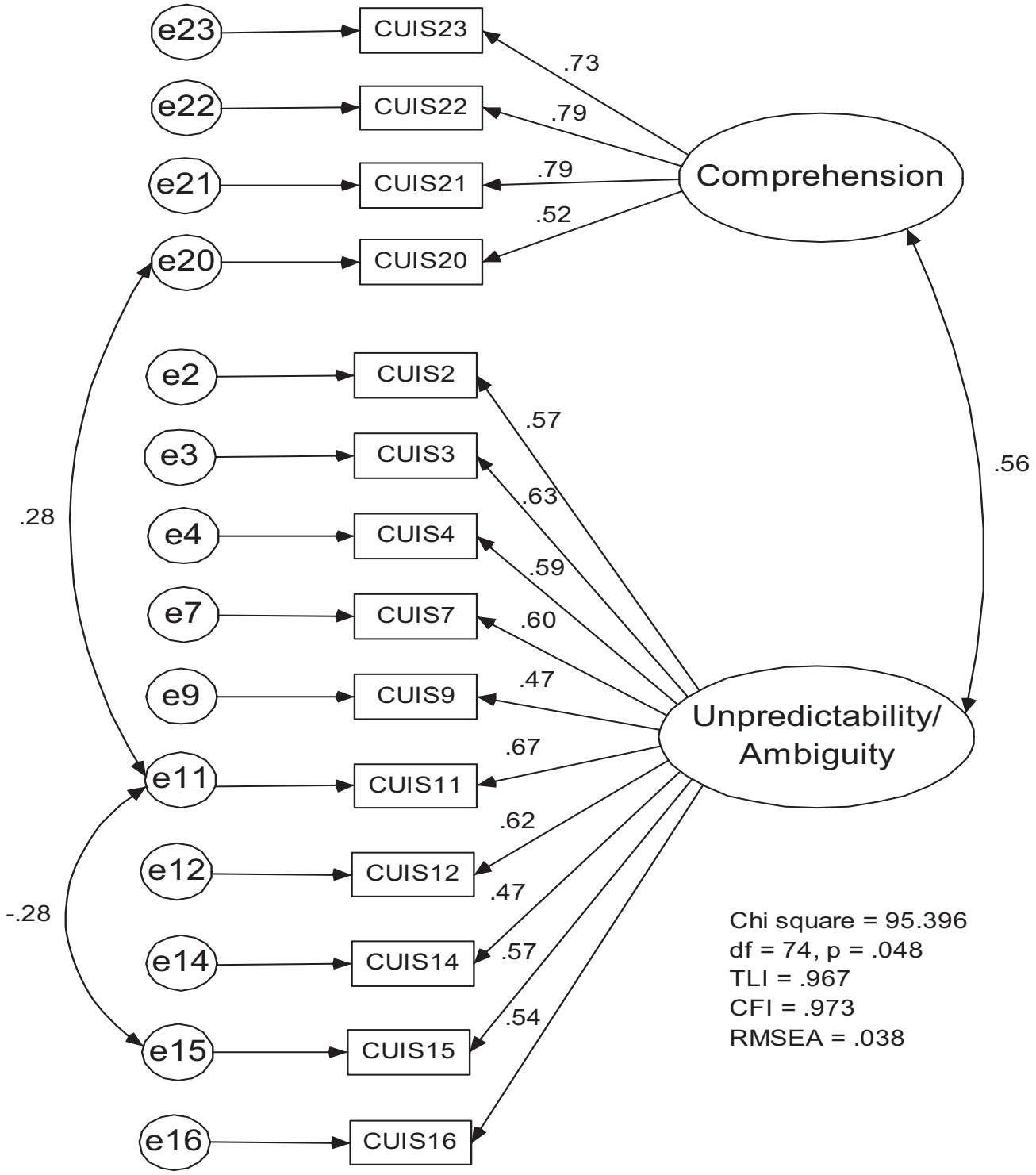

Figure 1. Final confirmatory factor analysis (CFA) model of the Child Uncertainty in Illness Scale (CUIS) for children with chronic health conditions ($n = 202$).

Ambiguity subscale ($r = .377$, $p = .000$, $n = 237$) and the Comprehension subscale ($r = .290$, $p = .000$, $n = 237$) were both significantly correlated with depression T scores. The differences in the correlations additionally support that the identified factors are distinct.

Discussion

To our knowledge, this study is the first to examine the factor structure of the CUIS using EFA and CFA in a relatively large sample of children with chronic health conditions. Our findings provide a contribution to the

Table II. Fit Indices for Each Model Tested for the Confirmatory Factor Analysis (CFA) and Multigroup Comparisons

Model step	χ^2	*df*	*p*	TLI	CFI	RMSEA
Confirmatory factor analysis (n = 202)						
1. Initial model	232.635	103	.000	.839	.862	.079
2. Item 13 removed	170.023	89	.000	.889	.906	.067
3. Added path between error terms for items 11 and 15	156.721	88	.000	.905	.920	.062
4. Removed item 8	108.952	75	.006	.948	.957	.047
5. Added path between error terms for items 11 and 20	95.396	74	.048	.967	.973	.038
Multigroup comparison factor analysis (8–12-year age group:						
n = 183; 13–18-year age group: n = 190)						
Unconstrained model	240.989	148	.000	.922	.936	.041
Constrained model	258.743	160	.000	.923	.932	.041
	$\Delta\chi^2$	Δdf	*p*	ΔTLI	ΔCFI	ΔRMSEA
Measurement weights	17.754	12	.123	−.001	.004	.000

CFI, Comparative Fit Index; RMSEA, Root Mean Square Error of Approximation; TLI, Tucker Lewis Index.

existing IU literature by further developing a standardized measure of IU for children and adolescents; the availability of such a measure and knowledge of its psychometric properties is critical to understanding the nature of uncertainty among children and how it is potentially related to a variety of psychological and health outcomes. The findings revealed two primary domains of child IU (e.g., Unpredictability/Ambiguity and Comprehension). Both the EFA and CFA yielded this two-factor structure, suggesting that each factor may be considered independently when scoring the CUIS. The Comprehension factor in this study differed from the Complexity factor of MUIS (Mishel, 1997), because the CUIS appears to measure the child's perception of their understanding and assimilation of information about their illness and treatment. Consistent with previous studies, the CUIS factors were associated with depressive symptoms supporting the validity of the shortened CUIS (Hoff et al., 2003; White et al., 2005). However, differences in the magnitude of associations of each factor with depressive symptoms suggest that each factor measures distinct aspects of the uncertainty experience.

This study extends previous research by an empirical identification of primary factors that contribute to a child's sense of uncertainty about their illness. The Unpredictability/Ambiguity factor was characterized by the inability to predict symptoms and condition outcomes, as well as ambiguity regarding the meaning of physical sensations and symptoms. For example, children with conditions characterized by symptom patterns that are highly variable in nature or are unsure how the condition will ultimately affect their ability to function may be at greater risk for experiencing uncertainty regarding their illness. The Comprehension factor was characterized by the child's level of understanding of the information about the condition and its outcomes. Hence, in situations where information related to the child's condition is incomplete or difficult to understand, the perceptions of uncertainty may be heightened. The Comprehension factor differs from the Complexity factor of the MUIS. The Complexity factor assesses the degree to which an individual perceives their treatment and system of care as having multiple, intricate, and varied components. In contrast, items on the CUIS Comprehension factor assess the degree to which the child understands the illness (e.g., The doctors and nurses explain things so I can understand, I know how bad my illness is).

Investigators examining the construct of child IU should be aware of the two-factor structure of the measure when examining the construct in relation to other psychological and illness-related outcomes. In addition, the version of the CUIS that yielded the best fit was comprised of fewer items than the original version, representing a more efficient measure. The shorter version of the CUIS could mitigate the participant burden associated with assessing child IU in the future. However, the present findings need to be replicated in independent samples to confirm the factor structure derived from the present CFA.

The current findings should be considered in light of several limitations. First, the sample was heterogeneous with regard to the chronic illnesses and ages of the children included in the study. Therefore, we cannot determine from the current analyses whether the factor structure would differ among other chronic illness groups. The heterogeneity of the sample provides an overall description of the nature of uncertainty among children with a chronic illness, enhancing the generalizability of the findings. Second, although multigroup comparisons indicated that the final model was valid for both children and adolescents, these results should be interpreted with caution due to the relatively small number of participants included in each age

group. Third, the lack of other standardized child IU measures also limits the conclusions that can be drawn regarding the construct validity of the measure. In addition, the limited number of studies using the CUIS lim it the extent to which definitive conclusions can be drawn about the reliability and validity of this measure. It should also be noted that the use of modification indices to guide CFA analysis increases the probability of the findings being influenced by chance. Finally, because the sample was relatively small, future investigations conducted with larger sample sizes are needed to replicate and expand upon the present findings.

A number of future directions for research on child IU were generated by the current investigation. Additional psychometric and normative data are needed before the CUIS should be used clinically, including studies that establish further construct, convergent, and discriminant validity of the instrument. Similarly, the validity and clinical utility of the measure should be further assessed by determining whether the two-factor model of the CUIS is related to critical outcomes other than psychological distress such as coping or adherence behaviors. The sensitivity of the CUIS to the type and duration of the condition changes in the condition course, and treatment regimens should be examined. Finally, the measure used in this study is not specific to any illness group; illness-specific measures that assess sources of uncertainty regarding the symptoms or treatment that may be unique to a particular condition could potentially yield a more sensitive and effective measure of this salient construct.

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