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Psychometric Evaluation of a New Instrument to Measure Uncertainty in Children with Cancer

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Abstract

Background—Although uncertainty has been characterized as a major stressor for children with cancer, it has not been studied systematically.

Objectives—To describe the development and initial psychometric evaluation of a measure of uncertainty in school-aged children and adolescents with cancer.

Methods—Interview data from the first author's qualitative study of uncertainty in children undergoing cancer treatment were used to generate 22 items for the Uncertainty Scale for Kids (USK), which were evaluated for content validity by expert panels of children with cancer and experienced clinicians (Stewart, Lynn, & Mishel, 2005). Reliability and validity were evaluated in a sample of 72 children aged 8 to 17 years undergoing cancer treatment.

Results—The USK items underwent minor revision following input from content validity experts and all 22 were retained for testing. The USK demonstrated strong reliability (Cronbach's alpha = .94, test-retest $r = .64$, $p = .005$) and preliminary evidence for validity was supported by significant associations between USK scores and cancer knowledge, complexity of treatment, and anxiety and depression. Exploratory factor analysis yielded 2 factors, not knowing how serious the illness is and not knowing what will happen when, which explained 50.4% of the variance.

Discussion—The USK, developed from the perspective of children, performed well in the initial application, demonstrating strong reliability and preliminary evidence for construct and discriminant validity. It holds considerable promise for moving the research forward on uncertainty in childhood cancer.

Keywords

child; uncertainty; measurement; cancer

Childhood cancer's evolution from a uniformly fatal condition to a life-threatening but potentially curable illness has contributed to a paradoxical context of increased optimism accompanied by pervasive uncertainty (Stewart, 2003). Uncertainty stems not only from the unknown outcome for any individual child, but also from such factors as an unpredictable illness trajectory; varying intensity and timing of toxicities and recovery; ambiguous

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symptoms; and concerns about the long-term impact of cancer and treatment on children's social, cognitive, and emotional competence. Although uncertainty has been characterized as a major stressor both during and following childhood cancer treatment, the impact of uncertainty on children's and adolescents' adjustment to cancer has not been studied systematically.

Most of the studies identifying uncertainty as an important aspect of childhood cancer and treatment have been retrospective, have relied on adolescents and young adults as informants, or both (Decker, Haase, & Bell, 2007; Novakovic et al., 1996; Zebrack & Chesler, 2002). Although valuable descriptive information about the uncertainties inherent in the childhood cancer experience has been provided, the results reflect cognitive and emotional insights gained with maturity and therefore offer limited insight into the concurrent experiences or perspectives of school-aged children. Stewart's (2003) exploratory, qualitative study of uncertainty in children undergoing cancer treatment partially addressed this knowledge gap by providing compelling evidence that children as young as 9 years old recognize and respond to the uncertainty inherent in cancer and treatment in ways that could affect their psychosocial adjustment significantly.

Mishel's (1988) Uncertainty in Illness theory has provided the framework for much of the research into adults' illness-related uncertainty, and has been employed in several studies with children and adolescents with chronic illnesses (Hoff, Mullins, Chaney, Hartman, & Domek, 2002; Neville, 1998; Van Pelt, Mullins, Carpentier, & Wolfe-Christensen, 2006; White et al., 2005). Uncertainty is described as the inability to determine the meaning of illness-related events or to predict an outcome accurately, and can be influenced by many illness-specific and individual factors (Mishel, 1988). Uncertainty can lead to psychological distress if coping responses are insufficient to resolve the uncertainty or to manage the negative emotional arousal if it cannot be resolved.

Central to Mishel's Uncertainty in Illness theory is the proposition that uncertainty results when a sufficient cognitive schema cannot be formed with which to interpret the meaning of illness-related events (Mishel, 1988). Although this proposition has not been tested specifically in children, there is evidence from the child psychology literature that by early school age, children rely on cognitive schemata in the context of illness (Hergenrather & Rabinowitz, 1991), and that illness-related uncertainty may interfere with children's capacity to form a sufficient schema within which to interpret subsequent illness experiences (Bearison, 1991). Further, Weisz (1990) has provided evidence that children experience heightened psychological distress when they are unable to determine the cause and therefore the controllability of events, a condition he refers to as *contingency uncertainty*. Appraisal of uncertainty thereby could represent the type of cognitive process that Thompson and Gustafson (1996) propose affects children's psychological adjustment to illness more profoundly than severity of the illness itself. Thus, the application of Mishel's theory to the study of children's and adolescents' uncertainty as a barrier to cognitive processing of illness-related experiences should make an important contribution to understanding of children's acute and long-term responses to cancer.

Definitive studies will require a psychometrically sound measure of uncertainty in children and adolescents with cancer. Mishel's Uncertainty in Illness Scale (MUIS; Mishel, 1981), developed and tested specifically in the context of adult illness, has been used in a limited number of published studies of children and adolescents. Mullins and Hartman (1995) adapted the Children's Uncertainty in Illness Scale (CUIS) from the MUIS for use with children and adolescents, and it has shown favorable reliability in multiple studies of chronic illness in children and adolescents. However, the assumption that the meaning of the construct being measured is the same as for adults has not been addressed specifically.

An approach to instrument development with considerable promise for contributing to the validity of self-report measures is using qualitative data to generate items indexing the construct under study. The emphasis in qualitative research on intensively and comprehensively understanding the dimensions, contexts, and relationships of a phenomenon echo the requirements for validity in quantitative measurement (Mishel, 1998; Strauss & Corbin, 1994). The same interview data which are used to develop the conceptual structure and dimensionality of the construct can provide the items which will index that construct, in the language and context of those who have experienced the phenomenon (Fleury, 1993). Qualitative research has been identified also as a particularly effective approach to representing the unique perspective of children (Siegal, 1991).

The purpose of this presentation is to describe the development and initial psychometric evaluation of an alternative measure of uncertainty derived from qualitative interviews with children undergoing treatment for cancer. No clear theoretical or empirical guidance for determining how the appraisal of uncertainty might change across the cognitive developmental spectrum was found in the literature, so the goal was to develop an instrument that could be used in both school-aged children and adolescents, such that future studies could address the nature and experience of uncertainty more systematically as a developmental phenomenon.

Methods

Design

The instrument was constructed using qualitative data from an earlier study of uncertainty in children undergoing cancer treatment (Stewart, 2003), and evaluated for content validity by two panels of experts (one composed of children and adolescents with cancer, the other of clinical nurse experts; Stewart, Lynn, & Mishel, 2005). Further psychometric evaluation was then conducted with a sample of 72 children and adolescents undergoing cancer treatment.

Development of the Uncertainty Scale for Kids

Interview data from the Stewart's (2003) qualitative study of uncertainty in children undergoing cancer treatment were used to generate items for the Uncertainty Scale for Kids (USK). Excerpts from the qualitative data that represented the three dimensions of children's uncertainty (not knowing, not being able to predict, and not being sure what things meant) were isolated from the 11 interviews and translated into items, keeping the phrasing as close to the child's syntax and context as possible. Every passage that had been coded as representing one of the three dimensions of uncertainty was used to generate a potential item. Eliminating redundancy resulted in a set of 22 items that represented the content derived from the qualitative data comprehensively. Using *post hoc* review revealed that 4 of the items corresponded to data coded as "not knowing," 12 to data coded as "not being able to predict," and 6 to data coded as "not being sure what things meant." Using the simplified measure of gobbledygook SMOG formula (McLaughlin, 1969), the reading level of the 22 items was determined to be third grade, which was deemed the desirable reading level, since the target age range for the instrument was 8 to 18 years. Since there are no published guidelines for a reasonable number of items on a self-report scale intended for use with younger children, all 22 items were retained for psychometric testing.

Two separate groups of experts were asked to review the 22 item stems for clarity, comprehension, and relevance. The first consisted of six children with cancer, three adolescents (aged 14–16 years) who had participated in Stewart's (2003) qualitative study, and three younger children (aged 8–11 years) who were undergoing cancer treatment. Each child met with the first author individually to carry out the content validity review. The second group consisted of four masters-prepared nurse clinicians with expertise in childhood cancer. Experts

in each group were asked to rate each item for its relevance to the content domain, as well as to suggest revisions that would improve its clarity and to identify content not indexed by the existing set of scale items. Following Lynn's (1986) quantification criteria for content validity, items were retained if five of the six child experts and all four of the nurse experts agreed that an item was relevant and acceptable. A detailed description of the procedures used to adapt standard content validity review procedures for children has been previously published (Stewart et al., 2005).

Once the final set of items was established, ordinal level scaling was added to provide children with an array of choices to represent their responses. A 4-point response format prompts respondents to indicate how often they felt unsure about each item, ranging from 1 (never) to 4 (always). This response format was chosen as a straightforward way for children and adolescents to represent intensity of uncertainty as the frequency with which they experience it.

Psychometric Evaluation

The USK, along with other study measures, was administered to participants aged 8 to 18 years who were undergoing treatment for any form of cancer. Participants were at various stages of treatment, including newly diagnosed, in remission, postrelapse, or awaiting or following stem cell transplantation.

Item analyses were conducted using interitem and corrected item-total correlations. Internal consistency was evaluated using Cronbach's alpha for the total scale. A subset of 25 subjects from a single institution (due to constraints on investigator resources) were asked to complete the USK a second time to evaluate test-retest reliability; a 1-week test-retest interval was chosen to minimize the degree of situational variability in uncertainty that can occur over relatively short periods of time (Mishel, 1988).

Support for the validity of the USK was evaluated by determining the associations with time since diagnosis, phase of treatment (continuous remission vs. active disease), intensity of treatment (chemotherapy +/− surgery), level of cancer knowledge, and psychological distress (anxiety and depressive symptoms). Based on Mishel's Uncertainty in Illness theory, it was anticipated that higher USK scores would be associated with less time since diagnosis, presence of active disease (vs. remission status), more intensive treatment, less cancer knowledge, and higher levels of anxiety and depressive symptoms.

Although the qualitative data used to generate the USK items suggested consistency between children's experiences with uncertainty and those indexed with the original MUIS (ambiguity, unpredictability, lack of information, and inconsistency), the dimensionality of the USK was not identified *a priori*, and therefore exploratory factor analysis (EFA) was used to examine the factor structure. Given the relatively low subject-to-item ratio (approximately 3:1), communalities (the proportion of item variance explained by the combined factors) were examined in order to assess the generalizability of factor extractions (Hogarty, Hines, Kromrey, Ferron, & Mumford, 2005). The quality of the final solution was evaluated with Kaiser/Meyer/Olken (KMO) measure of sampling adequacy (considered acceptable if > 0.75–.80), Bartlett's test of sphericity, the amount of variance explained, the relationship of items to factors (number of items per factor, item loadings ≥ 0.40, internal consistency of factors), and the theoretical meaningfulness of the resulting factors.

Procedures

Data were collected at four pediatric cancer centers affiliated with the Children's Oncology Group (COG), a cooperative study group representing most of the institutions across the United

States participating in cancer clinical trials research with children and adolescents. Approval for the study was obtained from each participating site's Institutional Review Board prior to identification of subjects and initiation of data collection. Potential subjects were excluded if they did not speak English, if they could not read at the second-grade level, or if in the opinion of their treatment team they were too ill to participate. Members of the treatment teams at the respective facilities were asked to identify and approach all eligible subjects; neither demographic data nor reasons for ineligibility were obtained for those deemed ineligible by the treatment team. Once a member of the clinical staff had determined the family's willingness to speak with the investigator, the investigator explained the study in detail and obtained consent from the parent and assent from the child, who was assured that participation in the study was not required even if the child's parent had given consent. The treatment team was not informed of the family's decision whether or not to participate.

Data collection took place at a location most convenient for the family. Overwhelmingly, families stated a preference to meet with the investigator at the treatment facility in order to minimize intrusion of illness-related issues into their daily lives; one parent asked the investigator to travel to the family's home, and the remaining participants completed study instruments in the inpatient or outpatient setting where they were receiving treatment. Questionnaires were read to all children aged 10 years and younger and to any participant who preferred to have the instruments read to them. When instruments were read out loud, the investigator met with the participant privately or asked express permission to conduct the data collection interview in the presence of the parent. Participants who completed the instruments independently were often in the same room as their parent, but no discussion of responses took place in front of the parent to ensure their responses remained confidential. Individual responses were not shared with parents or treatment team members. All consent forms and raw data were kept in a locked file within the primary investigator's home, and no identifying information was entered into the electronic data files used for analysis and reporting of findings.

The test-retest participants were given a copy of the USK to take home along with a stamped, self-addressed envelope for return to the investigator. The participants were asked not to attempt to remember their original answers but to respond to the questionnaires based on how they were feeling that day. Two children (aged 9 and 10 years) in the subset had the measures read to them by the investigator at initial data collection; the investigator reviewed the retest instrument with these children to determine that they were capable of completing the instrument themselves the second time. The investigator called participants on the day the retest was scheduled to remind them to complete and return the scales.

Additional Measures

Demographic and treatment characteristics—Parents provided the following information: child's date of birth, ethnicity, type and date of cancer diagnosis, and cancer treatment previously or currently received (chemotherapy, radiation, surgery to debulk or remove tumor tissue, hematopoetic stem cell transplant [HSCT], other). As indices of treatment intensity, children were classified as receiving chemotherapy alone or in combination with radiation, surgery, or both, as well as HSCT (yes/no).

Cancer knowledge—This investigator-developed scale was created for use in the current study, based on published cancer educational materials designed for children, and consisted of 12 true or false statements representing general information about childhood cancer and common side effects to treatment (e.g., hair loss, risk of infection, radioactivity). Because the intended sample was heterogeneous in type of cancer and treatments received, items were limited to general content; that is, not specific to any particular diagnosis or treatment modality. Missing responses were scored as incorrect. The scale score was constructed by summing the

number of correct answers for each subject. The scale was evaluated for content validity by the same four clinical experts who evaluated the USK; the experts agreed that each of the items were relevant, with three items undergoing minor revision to improve clarity. In this study sample, the KR-20 of 0.44, likely due at least in part to the high proportion of correct responses (> .60 for 11 of 12 items), indicates poor internal consistency. Item discrimination indices ranged from 0.11 to 0.52, with point biserial values for 5 of 12 items achieving significance. Cancer knowledge scores were positively correlated with age ($r = .36$, $p < .01$), indicating that older children had more cancer-specific knowledge.

Depressive symptoms—The Children's Depression Inventory (CDI; Kovacs, 1985) is a 27-item self-report scale that is used to elicit children's depressive symptomatology for the previous 2 weeks; it has first-grade readability. Each item has three response options, graded from 0 to 2 in the direction of increasing depressive symptomatology. Total scores are summed across items and range from 0 to 54. The CDI's reliability has been demonstrated by internal consistency coefficients ranging from .87 to .94 (Kovacs, 1985; Saylor, Finch, Spirito, & Bennett, 1984), including alpha = .89 in a sample of children with cancer (Phipps & Srivastava, 1997). The CDI has accumulated considerable evidence for reliability and construct, predictive, and discriminant validity in non-ill and chronically ill children (Carey, Faulstich, Gresham, Ruggiero, & Enyart, 1987; Wood et al., 2007; White et al., 2005). The Cronbach's alpha for the current sample was .80.

Anxiety—The Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds & Richmond, 1978) is a 28-item, self-report measure of children's anxiety and worry, and includes an additional 9 items to index social desirability response bias. Dichotomous responses are scored as 1 for yes or true for you and 0 for no or not true for you. Total scale scores are summed across each subscale and range from 0 to 28 for anxiety or worry and 0 to 9 for social desirability, with higher scores indicating higher levels of anxiety or worry or social desirability bias. Anxiety or worry and social desirability scores were correlated only modestly ($r = .15$, $p < .01$) in the original field test with 329 school children grades 1 through 12 (Reynolds & Richmond, 1978). Reliability for the anxiety or worry scale is supported by KR-20 estimates ranging from .83 to .85, and stability by 3-week test-retest correlation of .98 (Pela & Reynolds, 1982). The scale discriminates between anxious and nonanxious samples (Perrin & Last, 1992; Seligman, Ollendick, Langley, & Baldacci, 2004), strongly correlates with children's scores on the trait subscale of the State-Trait Anxiety Scale for Children (Reynolds, 1980), and has demonstrated adequate reliability and validity in samples of children with acute and chronic illness (DeMaso et al., 2000; Loney, Wirrell, Sherman, & Hamiwka, 2008). The KR-20 estimate of reliability for the current sample was 0.87.

Sample

Seventy-two children and adolescents undergoing cancer treatment constituted the sample for psychometric evaluation (Table 1). The mean age was 13 years ($SD = 2.9$ yrs). The sample was predominantly Caucasian (72%) and male (58%). Most of the participants had been diagnosed with leukemia or lymphoma (67%) and were in remission (68%). By far the most common treatment was chemotherapy (94%), with 42% also undergoing radiation, surgery, or both, and 11% having HSCT. Other than the underrepresentation of central nervous system (CNS) tumors, attributed to recruitment from pediatric oncology practices that typically see patients with CNS tumors only when they are treated with chemotherapy, the sample characteristics are generally representative of the population of children with cancer treated in the Southeastern United States. The mean time since diagnosis (18.6 months, $SD = 24.2$) was skewed by two participants with long illness durations, and thus the median of 11.9 months is more representative of central tendency. Because of this major departure from the normal distribution, the natural logarithm of the months since diagnosis was calculated to create the

variable *time since diagnosis*. This new variable more closely approximated a normal distribution with a mean of 2.4 (*SD* = 1.1).

Ten eligible children and adolescents (6 boys and 4 girls, mean age = 12.5 years, all Caucasian) declined participation in the study and 3 mothers (all with Caucasian girls, mean age = 10 years) declined their child's participation in the study, yielding a refusal rate of 15.3%. One 15-year-old said she had no uncertainty because of her strong faith in God; the other 9 who refused said they were simply not interested. One mother was concerned that introducing the USK would raise the issue of potential bad outcomes for her child; one mother was generally skeptical of psychosocial research; and one mother expressed that her family was too overwhelmed with the diagnosis to participate at that time.

Results

Content Validity

For 20 of the 22 original items, at least five of the six child experts agreed that the item was *good* or *okay*. These items were retained as written or with minor revisions based on the children's comments. The two items that did not meet the standard were reworded substantially after addressing children's comments about why these items were irrelevant or how they could be improved. All four clinical experts agreed that each of the 22 items was relevant. None of the child or clinical experts identified additional relevant content. The 22 items incorporating the children's input constituted the set of items subjected to further psychometric evaluation.

Item Analyses

Item means, standard deviations, and corrected item-total correlations are presented in Table 2, ranked by item means. The majority of interitem correlations ranged between 0.30 and 0.70, with the exception of one item (*How I got cancer*) that showed correlations below 0.30 with 18 of the remaining 21 items. Similarly, this item's corrected item-total correlation (0.29) was the only one that was below 0.30.

Reliability

The USK demonstrated strong internal consistency with Cronbach's alpha = 0.94. The 1-week test-retest reliability was moderately strong ($r = .64$, $p = .005$).

Validity

As predicted, USK scores were correlated moderately with anxiety ($r = .56$, $p < .001$) and depressive symptoms ($r = .59$, $p < .001$; Table 3). The USK was not correlated significantly with time since diagnosis or with cancer knowledge, although the valences were in the expected direction. *Post hoc* exploratory analysis demonstrated that cancer knowledge was correlated significantly with age ($r = .36$, $p < .001$); when age was controlled, the correlation of USK scores with cancer knowledge remained weak but achieved significance ($r = -.27$, $p = .02$). The USK scores showed no correlation to stage of treatment (remission vs. other stage of disease). Participants who were treated with chemotherapy alone had lower USK scores (mean = 44.4, *SD* = 14.2) than those who had also undergone surgery, radiation, or both (*M* = 55.8, *SD* = 15.0, $t_{63} = 3.06$, $p = .003$). A similar but nonsignificant trend was seen in children and adolescents who underwent HSCT (*M* = 59.0, *SD* = 14.4) versus those who did not (*M* = 48.5, *SD* = 15.6, $t_{70} = 1.80$, $p = .08$).

Dimensionality

Bartlett's Test of Sphericity was significant (approximate $\chi^2 = 977.06$, $df = 231$, $p < .001$) and the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was robust at 0.893,

providing evidence for an ample number of significant correlations among items to justify proceeding with factor analysis. Principal Axis Factoring (PAF) was performed initially with an orthogonal (Varimax) rotation, which converged in 3 iterations and yielded 4 factors with Eigenvalues > 1.0 that explained 56.6% of the variance. However, the scree plot demonstrated a clear elbow between the second and third factors. The first factor contained 12 items with factor loading values ranging from .47 to .79, and the second factor contained 7 items with factor loadings from .43 to .66. The third and fourth factors each had only 1 item, and one item did not load on any of the factors. Therefore, PAF with Varimax rotation was repeated extracting only two factors, which accounted for 50.4% of the variance. Thirteen items loaded on the first factor, eight items on the second factor, and one item (*How I got cancer*) loaded on neither factor. There was mild cross-loading between the two factors. The summed scores for the items loading on each of the two factors were correlated strongly ($r = .72$) and, therefore, PAF was repeated extracting two factors using oblique (Oblimin) rotation. The rotated solution was essentially the same, except that one item (*What exactly is making me feel sick*) which had loaded previously on both factors now loaded weakly on the first factor. Estimated item communalities, factor loadings (pattern matrix coefficients are reported; structure matrix coefficients are available upon request), and item-factor correlations for this obliquely rotated solution are presented in Table 4.

Many of the 12 items that loaded on the first factor related to not being able to tell how serious the illness is overall or at any given moment, represented by items such as *Whether or not I'm doing okay* and *If I'll miss out on fun things because of my cancer*. The average interitem correlation of .60 (range .46–.72) and Cronbach's alpha = 0.95 indicated strong internal consistency and possible item redundancy. The 8 items that loaded on the second factor related more to not knowing exactly what will happen day to day, represented by items such as *If treatments will happen when they are scheduled* and *What side effects I'm going to have*. The average interitem correlation of .39 (range .24 to .65) and Cronbach's alpha = .84 indicated strong internal consistency for the second factor.

Discussion

The USK, developed from the perspective of children and adolescents with cancer and shaped by the contributions of child content validity experts, performed well in the initial application, demonstrating strong reliability and preliminary evidence for validity. The strongest evidence for construct validity is provided by the robust correlation of USK scores with both anxiety and depression, consistent with the theoretical premise that in the absence of effective management strategies, uncertainty can lead to psychological distress. The association with situational factors that may inhibit the development of an adequate cognitive schema and thereby increase uncertainty was less consistent. The higher USK scores for children and adolescents undergoing more complex treatment regimens provides preliminary support for discriminant validity, and the weak association between cancer knowledge and USK scores when age is controlled is additional, albeit modest, evidence for construct validity. Statistical problems with the measures for both time since diagnosis (significantly skewed) and cancer knowledge (low internal consistency), as well as crude indices of treatment intensity and phase of treatment, may have compromised the detection of additional relevant associations. Further studies to evaluate the validity of the USK are warranted. It would be particularly useful to compare scores on the USK, conceptualized as an illness-specific measure of uncertainty, with the MUIS (Mishel, 1981) or the CUIS (Mullins & Hartman, 1995), which are used to measure uncertainty in nonspecific illness contexts. Such a comparison would provide additional information about the USK's validity as well as insight into the contexts most appropriate for using the various instruments.

The EFA suggests that two related dimensions may contribute to children's and adolescents' uncertainty during cancer treatment. Not being able to determine the seriousness of the illness is consistent with Mishel's characterization of ambiguity as the inability to determine the meaning of illness-related events, whereas not knowing exactly what will happen when reflects the unpredictability of the treatment trajectory. The single item indexing etiologic uncertainty--not knowing how one got cancer--demonstrated less quantitative evidence for indexing the central construct. However, 63 of the 72 participants indicated that they felt unsure about it at least some of the time, with 20 indicating they felt unsure about it all the time. Therefore, all 22 items should be retained for further psychometric evaluation. If the factor solution demonstrates stability and the Cronbach's alpha remains high as an indication of possible item redundancy, the total number of items could be reduced to limit subject burden.

The primary limitation of this study was the relatively small sample size, although the moderate to strong item communalities, particularly in light of the limited number of extracted factors and probable overidentification of the first factor, as well as the robust KMO measure, argue for stability of the factor solution (Hogarty et al., 2005). In addition, while reflecting the typical population of children with cancer seen in United States centers, the sample demonstrated limited racial and ethnic variability. The previously detailed measurement problems as well as the low subject-to-item ratio also limited the evaluation of validity. A second field test with a larger sample of children and adolescents with cancer would provide additional information about the validity of the USK and contribute to a better understanding of the dimensionality of children's and adolescents' uncertainty.

Research into the experiences of families facing childhood cancer have relied heavily on the perspectives of parents or adolescents looking back on their time in treatment, and as such have failed to capture the true complexity of influences on individual and family functioning. Despite the characterization in the literature of childhood cancer as inherently uncertain, few researchers have investigated uncertainty specifically from children's perspectives, and therefore the impact of uncertainty on children's adjustment has been largely unexamined. Given that the USK shows promise as a psychometrically sound instrument to measure uncertainty in children and adolescents, the previous work on uncertainty in the context of childhood cancer can be expanded to incorporate the perspectives of children as young as 8 years into an understanding of how living with such an illness affects families.

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Table 1

Sample Characteristics

	Mean	Standard Deviation	Median	Range
Age in years	13.0	2.9	13	8 – 18
Grade in school	8	2.7	8	1–12
Months since diagnosis	18.6	24.2	11.9	.2 – 166
	n	%		
Sex				
Male	42	58.3		
Female	30	41.7		
Ethnicity				
African American	15	20.8		
Asian American	2	2.8		
Caucasian	52	72.2		
Hispanic	2	2.8		
Native American	1	1.4		
Diagnoses				
Leukemia/Lymphoma	48	66.7		
Solid tumor	17	23.6		
Central Nervous System	6	8.5		
Stage of illness				
Newly diagnosed	11			
Remission	49	15.3		
Relapsed		68.1		
Type of treatment				
Chemotherapy	68	95.8		
Radiation	18	25.4		
Surgery	12	16.7		
HSCT	8	11.3		

Notes. HSCT = hematopoetic stem cell transplantation

Table 2

Item Means, Standard Deviations, and Corrected Item-Total Correlations

Item	Mean	Standard Deviation	Corrected Item- Total Correlation
If I'll miss out on fun things because of my cancer	2.77	1.2	.70
Why cancer happened to me	2.75	1.1	.70
When I will be through with all of this	2.66	1.2	.73
If everything will go all right	2.54	1.2	.80
How I got cancer	2.53	1.0	.29
How things are going to come out	2.53	1.1	.73
What's going to happen next	2.51	1.1	.76
How bad the treatment will make me feel	2.44	1.1	.66
Which side effects I'm going to have	2.37	1.0	.62
Whether or not I'm doing okay	2.32	1.0	.73
If things will go according to the plan	2.30	1.1	.78
If something bad might show up in my tests	2.30	1.0	.77
What exactly is making me feel sick	2.28	1.1	.54
If I'm going to get better or not	2.24	1.2	.70
When I feel sick, is it serious or no big deal	2.15	1.0	.70
How much treatment I have to get	2.08	.9	.47
What is going on with me	2.07	1.0	.76
If there will be any surprises when I get a treatment	2.03	.9	.54
If my cancer is getting worse	1.99	1.0	.71
If treatments will happen when they are scheduled	1.86	1.0	.53
Whether I'm being told the truth	1.70	1.0	.42
Why I have to get treatment	1.65	1.0	.39

Table 3

Zero-Order Correlation Coefficients, Means, and Standard Deviations for Study Variables

	Uncertainty	Time Dx	Stage	Knowledge	Anxiety	Mean (*SD*)
Uncertainty						49.9 (15.7)
Time Dx[a]	−.23					2.4 (1.1)
Stage[b]	.06	−.27*				
Knowledge	−.15	−.06	−.10			9.5 (1.7)
Anxiety	.56**	−.02	−.10	−.20		10.0 (6.2)
Depression	.59**	−.13	−.07	−.09	.59**	7.4 (5.4)

Notes.

* $p < .05$,

** $p < .001$

[a] natural logarithm of months since diagnosis;

[b] stage of illness (1 = remission, 0 = not in remission)

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Table 4

Principal Axis Factoring with Oblimin Rotation, the Uncertainty Scale for Kids

Item stem	Estimated Communality	Factor 1		Factor 2	
		Factor Loading[a]	Item-Factor Correlation[b]	Factor Loading[a]	Item-Factor Correlation[b]
Whether or not I'm doing okay	.771	1.013	.81		
If my cancer is getting worse	.733	.842	.74		
How things are going to come out	.715	.820	.76		
If I'm going to get better or not	.693	.798	.74		
If everything will go all right	.778	.787	.82		
If something bad might show up in my tests	.722	.755	.79		
What is going on with me	.739	.707	.76		
When I will be through with all of this	.733	.690	.75		
What's going to happen next	.693	.649	.76		
If things will go according to the plan	.809	.586	.74		
If I'll miss out on fun things because of my cancer	.631	.579	.69		
Why cancer happened to me	.573	.516	.68		
What exactly is making me feel sick	.491	.345	.51		
If treatments will happen when they are scheduled	.535			.739	.61
How bad the treatment will make me feel	.679			.705	.69
How much treatment I have to get	.603			.644	.57
When I feel sick, is it serious or no big deal	.638			.633	.67
If there will be any surprises when I get a treatment	.604			.460	.52
Why I have to get treatment	.436			.455	.44
Whether I'm being told the truth	.473			.438	.44
Which side effects I'm going to have	.532			.436	.57
How I got cancer	.334				

Notes.

[a] Pattern matrix coefficients; values below .30 suppressed,

[b] Corrected item to factor correlation