

Living With a Chronic Illness: A Measure of Social Functioning for Children and Adolescents

Christina D. Adams,¹ PhD, Randi M. Streisand,² PhD, Tricia Zawacki,² PhD, and Karen E. Joseph,¹ MA

¹West Virginia University and ²University of Florida

Objective: To describe the development and initial psychometric evaluation of a measure of social functioning in children and adolescents with chronic medical conditions, Living with a Chronic Illness (LCI), designed to distinguish social difficulties related to the illness from those social difficulties associated with other factors (e.g., limited income).

Methods: Parents ($n = 108$) and youths ($n = 115$) completed the LCI, along with other psychological measures (e.g., Youth Self-Report). Teachers completed the Teacher Report Form and provided grade and absence data. Health care utilization data were obtained from medical charts.

Results: Statistical analyses supported the internal consistency and initial validity of LCI scores. Correlational results strongly point to the distinction made between illness-related and non-illness-related social difficulties and suggest that the LCI has some relation to existing measures (e.g., Child Behavior Checklist), while still providing a unique perspective on children's social functioning. Univariate and regression analyses revealed significant relations between LCI scores and health care utilization.

Conclusions: These findings support the initial psychometric properties and clinical utility of the LCI scores. We discuss strengths and limitations of this study, as well as potential clinical applications for the LCI questionnaire.

Key words: *chronic illness; social functioning; children; adolescents; assessment.*

The examination of social functioning in children with a chronic illness is an unquestionably important area of study. Even among healthy populations, peer relations can be a good indicator of current as well as longer-term emotional adjustment (Hartup, 1983; Parker & Asher, 1987). Within chronic illness, observed changes in a child's social functioning could potentially serve as a behavioral marker to parents and health care professionals of possible difficul-

ties in the child's disease management, adherence, or adjustment to illness.

Despite the importance and potential clinical implications regarding social functioning, pediatric psychologists continue to face substantial challenges in designing investigations of this construct. These challenges include those typically encountered by pediatric researchers, such as limited access to participants, large number of treatment/procedural demands already placed on children and families, and need for multidisciplinary collaboration (Drotar, 1989). Also, the construct of "social functioning" is

All correspondence should be sent to Christina D. Adams, West Virginia University, Dept. of Psychology, P.O. Box 6040, Morgantown, West Virginia 26506-6040. E-mail: Christina.Adams@mail.wvu.edu.

difficult to define. Generally, social functioning is meant both to be an index of children's interest and performance across several areas, including how easily they make friends and get along with other children (e.g., peers and siblings), assimilate into social groups (e.g., organized youth clubs), and negotiate other activities (e.g., school, extracurricular activities, and sports). Thus, "social functioning" can be considered as a catchall description encompassing children's peer relations, social competence, and social-emotional adjustment.

Though some may argue that social functioning/adjustment and quality of life are interchangeable terms, quality of life is multidimensional and incorporates physical symptoms and psychological functioning (Aaronson, 1988; Landgraf & Abetz, 1995). Consequently, quality of life measures tend to have an insufficient number of items devoted to assessing social functioning specifically and therefore may be less adequate and less reliable indicators of social functioning. Because social functioning is an integral area of a child's life, and other domains (e.g., work functioning) often assessed in quality of life measures may be irrelevant to many youths, quality of life measures are less than ideal instruments for measuring social functioning in children. Further, many quality of life measures that assess adjustment to illness, such as the Diabetes Adjustment Scale (Sullivan, 1979), have restricted specificity to one illness group only.

Along with these barriers to studying social functioning in children with chronic illness, relatively few social assessment tools specific to pediatric populations exist. Given the absence of such measures, researchers often face the dilemma of using measures designed for physically healthy children (e.g., the Harter Perceived Competence Scale; Harter, 1985), modifying adult measures of psychosocial adjustment to illness, or developing their own questionnaire for use in a particular investigation. The challenges and potential pitfalls of using general child measurement tools with pediatric populations have been discussed (La Greca, 1994; Perrin, Stein, & Drotar, 1991), and the most salient difficulties include the following: (1) lack of useful normative data, (2) child's physical health can affect outcome scores in various ways, and (3) clinical child measures generally are designed to differentiate between psychopathology and normalcy versus showing a continuum of functioning that might be beneficial to examine within illness groups. Adapting illness adjustment measures designed for adults with illness to measures of child so-

cial adjustment to illness is problematic because of the different readability levels between adults and children, different arenas of social functioning pertinent to adults versus children, and the fact that many illness adjustment measures for adults assess other areas besides social adjustment. Finally, developing project-specific measures of social functioning for investigations is inefficient, costly, and time-consuming; by doing so, inconsistency occurs across research, making it difficult to contrast and interpret findings. Professionals agree that more appropriate assessment tools must be developed for children with chronic illness (Van Dongen-Melman, De Groot, Hahlen, & Verhulst, 1996).

In response to the lack of available pediatric-specific tools to assess adjustment, we designed a questionnaire to measure more appropriately the impact of childhood chronic illness as it relates to a child's social functioning. Specifically, we were interested in creating a measure that could be used with a wide age range of children having a variety of chronic illnesses. Such a measure would enable researchers with different subspecialties in pediatric psychology to measure consistently the construct of social functioning across illness groups. Holden, Chmielewski, Nelson, Kager, and Foltz (1997) also contend that study findings may be generalized more readily when illness adjustment is examined for an array of illnesses. Furthermore, by including several chronic illnesses, we planned to begin establishing normative data to be utilized by future researchers within the field of children's health. Our intent was to include a broad range of the most common pediatric chronic health conditions (see Table I).

One might argue that a non-illness-specific measure of social functioning is problematic in that illnesses affect social functioning differently. We considered that children with different illnesses might have social difficulties in different areas and consequently created a measure with a variety of social issues that we thought would vary in salience to different illness groups. In addition to considering the possibility of between-group differences in social functioning, we also considered the likelihood of within-group differences in social functioning due to within-group factors such as illness severity. Our intention was to create a measure that would capture differences in social functioning both between and within illness groups. Yet we had no specific hypotheses regarding between- and within-group variations in social functioning; rather, these questions were exploratory.

Table 1. Chronic Illness Groups

Group	<i>n</i>	%
Asthma (AS)	20	17.4
Seizure disorder (SZ)	20	17.4
Cancer (CA)	20	17.4
Arthritis/lupus (AL)	12	10.4
Sickle cell disease (SC)	10	8.7
Cystic fibrosis (CF)	5	4.3
Other (e.g., organ transplant, headaches)	28	24.3

Regarding the measure's content, we strove to incorporate three main areas within a child's social functioning: home, school, and extracurricular activities. We also believed it was important to gather information related to the child's satisfaction or level of content within these social areas rather than simply assuming that a child was poorly adjusted or unhappy because he or she did not attend social gatherings or had only a few close friends, for example. This approach is in contrast to how most non-illness-specific measures are designed. For example, the Social Competence scale of the Youth Self-Report (Achenbach, 1991c) measures the child's number of close friends, as well as frequency of contact with them; the measure does not take a child's satisfaction into account, and it is possible to obtain a clinically significant score yet feel content with one's social contacts. Furthermore, we wanted to create a measure that could be completed by both parents and youths. Study designs often have failed to include multiple informants, even though children's own report of social functioning, mood, or internalizing behavior may be very different from that of their parent, for example (Rodrigue, Streisand, Banko, Kedar, & Pitel, 1996).

Our primary objective, however, was to construct an instrument with sound, initial psychometric properties. We hypothesized that the Living With Chronic Illness (LCI) instrument would demonstrate satisfactory levels of internal consistency. Moreover, in support of its validity, we anticipated that LCI illness-related scores would be significantly and most highly associated with measures of social competence, as well as other areas of perceived competence (e.g., physical appearance, self-worth), across informants (i.e., youths, parents, teachers). Finally, based on research that has shown a direct relation between child health care utilization and child psychosocial problems (Kinsman, Wildman, & Smucker, 1999), we hypothesized that children with higher health care utilization rates would have more problems in social functioning.

Method

Phase I: Questionnaire Development

Item pool development for the LCI scale involved (1) reviewing the literature, (2) incorporating the clinical experience of various physical and mental health care providers, and (3) informally interviewing pediatric patients with chronic illness and their parents. A noncategorical disease approach was taken during item development. In other words, items were created based on dimensions that have been identified as cutting across pediatric chronic illnesses (La Greca, 1990). Such dimensions include restriction of physical activity (e.g., athletics), interruption of daily activities (e.g., school), changes in physical appearance (e.g., loss of hair), and modifications in lifestyle (e.g., dietary restrictions). Three physicians with different pediatric specializations and two pediatric psychologists reviewed and subsequently modified LCI items.

The LCI scale consists of a parent form (LCI-P) and youth form (LCI-Y). The LCI-Y is intended for children and adolescents between the ages of 9 and 18 years. A Flesch Kincaid analysis revealed that parents completing the LCI-P require a 5.0 grade reading level and children completing the LCI-Y require a 4.6 grade reading level. The LCI-P and the LCI-Y each consist of the same 29 items. Both forms include a dichotomous, true/false response format (see Figure 1 for sample item format). If the respondent indicates false, he or she is directed to move on to the next item. True responses require the respondent to continue with the current item. Specifically, the respondent is instructed to (1) endorse "yes" or "no" to the question "is it because of the illness or treatment," and (2) indicate how much the problem addressed in the item "upsets" the child. Response options for this latter question include "not at all" (0), "just a little" (1), "pretty much" (2), and "very much" (3). A sample item on the LCI-P includes "other children do not invite my child to play or take part in fun activities," and a sample item on the LCI-Y includes "I do not play team sports (examples: soccer, football, softball)." Two scores are derived each from the LCI-P and LCI-Y: an illness difficulties (ID) score and a nonillness difficulties (NID) score. The ID consists of the sum of all Likert ratings on the question "how much does the problem upset the child" for problems previously endorsed as due to the child's illness (i.e., "yes" responses to the illness question). The NID consists of the sum of all Likert ratings on the question "how much does the problem upset the child" for problems

HOW UPSET IS YOUR CHILD?

		True or False?		Is it because of the Illness?		Not At All	Just A Little	Pretty Much	Very Much
1.	My child misses school.	T	F	Y	N				
2.	My child does not take part in school activities (Example: social groups, pep rallies).	T	F	Y	N				

Figure 1. Sample item format from the LCI-P.

previously endorsed as *not* due to the child's illness (i.e., "no" responses to the illness question).

One unique feature of the LCI scale is that it differentiates and provides a separate score for two different types of problems: those associated with the illness and those not associated with the illness, such as problems related to lack of opportunity or socioeconomic status (SES). Equally unique, the LCI also identifies social areas that function as "problems" for children with a chronic illness by asking the respondent to identify how "upset" the child is regarding components of social functioning.

Phase II: Psychometric Properties **Participants**

One hundred and eight parents of children with a chronic illness completed the LCI-P. The adult sample consisted of 86% mothers, 12% fathers, and 2% other. Mothers predominated in the adult sample because they were the ones who most often brought the children to clinic visits. The lack of father participants, though unfortunate, is not surprising in light of other studies (e.g., Adams et al., 2001) that have shown that mothers are the primary caregivers responsible for the medical management of a pediatric chronic illness. Adult participants ranged from 27 to 53 years of age ($M = 38.6$ years, $SD = 6.2$ years). Families came from a range of economic backgrounds. Annual income levels were as follows: 33% at less than \$15,000; 24% earning \$15,000–\$24,999; 16% having \$25,000–\$34,999; 10% at \$35,000–\$49,999; and 17% earning \$50,000 or more. The modal educational level for both parents was to have graduated high school and either attended some college or completed a vocational training program. Approximately 17% and 30% of mothers and fathers, respectively, had not completed high school, whereas nearly 12% and 18% of mothers and fathers, respectively, had earned bachelor's or graduate degrees.

The LCI-Y was completed by 115 children between the ages of 9 and 18 years ($M = 13.2$ years, $SD =$

2.7 years). The youths were 54% male and 46% female. Racially, the child sample was 69% Caucasian, 29% African American, and 2% other minority (e.g., Hispanic American). Categories of chronic health conditions are displayed in Table I. All participants were recruited from pediatric clinics (e.g., Hematology/Oncology, Pulmonary, Neurology) at the University of Florida Health Sciences Center.

Additional Measures

Demographic and Medical Information Form. The Demographic and Medical Information Form obtained demographic and medical background information pertaining to the patient (e.g., health care utilization) and his or her family (e.g., parental education). The parent form was delivered as a paper-and-pencil measure, while the youth form used a semistructured interview format.

Child Behavior Checklist. The Child Behavior Checklist (CBCL; Achenbach, 1991a) is a parent-report measure of general psychopathology in children between the ages of 4 and 18 years. The CBCL yields age- and gender-based T-scores for social competence, a total behavior problem score, and two broadband scores (i.e., "internalizing" and "externalizing" behavior). Further, scores may be calculated for eight narrow-band scales representing individual, psychological factors (e.g., "anxious/depressed"). Achenbach reports good psychometric properties for the CBCL. Total raw scores (as suggested in the manual; Achenbach, 1991a), for Internalizing Problems, Externalizing Problems, and Social Competence scales were used in data analyses.

Youth Self-Report. The Youth Self-Report (YSR; Achenbach, 1991c) is a 112-item, self-report measure of psychopathology developed for adolescents between the ages of 11 and 18 years. The scales and subscales derived from the YSR are the same as those obtained from the CBCL. Additionally, the majority of the items on the YSR correspond to those on the CBCL. The YSR has adequate psychometric proper-

ties (Achenbach). Total raw scores for Internalizing Problems, Externalizing Problems, and Social Competence scales were used in data analyses.

Teacher Report Form. The Teacher Report Form (TRF; Achenbach, 1991b) is a 113-item, teacher-report measure of multiple domains of behavior problems in children between the ages of 5 and 18 years. Like the YSR, each of the subscales and the majority of items on the TRF are identical to those of the CBCL. Satisfactory internal consistency estimates have been found for the behavior problem scales (Kamphaus & Frick, 1996). Total raw scores for Internalizing Problems and Externalizing Problems scales were used in data analyses.

The Self-Perception Profile for Children. The Self-Perception Profile for Children (SPPC; Harter, 1985) is a 36-item self-report measure of perceived competence in children between the ages of 8 and 12 years. In this study, the SPPC was administered to participants 8–12 years old. The SPPC yields six scales: scholastic competence, social competence, athletic competence, physical appearance, behavioral conduct, and global perceived competence. Each item provides a 4-point structured alternative response format, with 1 indicating low perceived competence and 4 indicating high perceived competence. Harter reports satisfactory reliability and validity for the SPPC. For the current investigation, the total raw score for all subscales (possible range of 6–24 for each) was used in relevant data analyses.

The Self-Perception Profile for Adolescents. The Self-Perception Profile for Adolescents (SPPA; Harter, 1988) is a 45-item measure of competence in adolescents between the ages of 13 and 18 years. For our study, the SPPA was administered to all participants 13 years and older. The SPPA yields the same six scales as does the SPPC, plus three additional domains derived from factor analysis (i.e., job competence, romantic competence, friendship competence). Each item of the SPPA has the same response format as the SPPC. The SPPA has satisfactory internal reliability (Harter) and meets standard validity requirements (Sherrill, Hinson, Gench, Kennedy, & Low, 1990). For this investigation, the subscale total raw scores (possible range of 5–20 for each) were used in relevant data analyses.

School Information Form. The School Information Form (SIF) obtained school absence and grade point average (GPA) information. To enhance the validity of information attained, this form was designed for teacher (as opposed to child or parent) completion.

Medical Chart Review Form. The Medical Chart Review Form was designed to gather the following

specific information from participants' medical records: the frequency of clinic visits, number of hospitalizations, and other health utilization variables across the 6 months preceding participation in the study. Medical charts for 110 participants were available, and reviews were completed by one of the four authors.

Procedure

The hospital institutional review board approved study procedures. A trained research assistant approached families for participation at the time of the child's clinic appointment. After informed consent and assent were obtained, parents completed the Demographic and Medical Information Form, LCI-P, and CBCL. It took parents approximately 5 to 10 minutes to complete the LCI-P. Most parents completed the instrument on their own without difficulty in reading or comprehension. Children were administered the semistructured interview (Demographic and Medical Information) and then were assisted as necessary with completing the remaining self-report questionnaires. It took children approximately 5 to 15 minutes to complete the LCI-Y. Most children were able to complete the LCI-Y independently after having had the first item or two demonstrated to them. The youngest children appeared to understand the wording of the LCI-Y; however, some of them had difficulty with the item format. A research assistant was available at all times to assist children with completing the LCI-Y as necessary. Teachers were mailed the TRF and SIF to complete and return via self-addressed, stamped envelopes. Forty-six teachers (approximately 40% of the sample) returned the forms.

Results

We conducted statistical analyses to evaluate the basic psychometric properties and initial clinical utility of LCI scores. First, the reliability or internal consistency of LCI scores was calculated, after which descriptive statistics (i.e., *M*, *SD*) of LCI scores and related measures were performed. To determine the relations among LCI scores, correlational analyses were conducted. Next, to assess convergent and divergent validity, LCI scores were correlated with other measures. Univariate analyses were then performed to investigate demographic and illness group differences in LCI scores. Finally, we used regression analyses to assess whether health care utilization significantly predicts illness-related problems in these chronically ill participants.

Table II. Percentage of Respondents Endorsing Items as Problematic

Item content (paraphrased)	LCI-P		LCI-Y	
	<i>n</i>	%	<i>n</i>	%
Misses school ^{a,b}	32	32.3	18	18.0
Does not take part in school activities	15	15.3	5	5.1
Left out from activities or games w/other children	15	15.3	8	8.0
Does not play team sports ^b	26	26.5	10	10.0
Has problems making or keeping friends	8	8.2	3	3.0
Is teased by other children about appearance	9	9.1	5	5.0
Does not take part in outdoor exercise sports ^b	7	7.1	3	3.0
Is treated differently than classmates by teachers	8	8.2	3	3.1
Is not as independent as other children the same age	11	11.1	5	5.0
Does not take part in social activities after school	9	9.1	7	7.2
Does not take part in social clubs or organizations ^b	9	9.3	2	2.0
Has school grades below average ^a	4	4.2	3	3.1
Has problems getting along with family ^{a,b}	4	4.1	2	2.0
Feels different from other children the same age	19	19.4	5	5.1
Feels uncomfortable or uneasy in social events	8	8.1	4	4.1
Does not like others to know about diet, medication, etc. ^a	15	15.5	6	6.1
Does not get along with people outside the family ^a	1	1.0	1	1.0
Does not do as many activities as siblings do ^b	6	6.3	3	3.2
Does not play outside often ^b	10	10.3	1	1.1
Is teased by others	8	8.2	8	8.2
Does not get along with children the same age	3	3.1	0	0.0
Does not take part in many family activities	2	2.0	1	1.0
Is not able to travel ^a	1	1.0	1	1.0
Does not start new projects at school or home	4	4.1	0	0.0
Does not do chores at home ^{a,b}	4	4.1	1	1.0
Is ignored by other children	4	4.1	3	3.0
Has fewer friends than classmates do	8	8.2	1	1.0
Does not regularly take part in physical education classes ^b	11	11.3	7	7.2
Is not invited to play or take part in fun activities	3	3.1	2	2.0

^aCorrected item-to-total correlation coefficient is less than .30 for the LCI-P.

^bCorrected item-to-total correlation coefficient is less than .30 for the LCI-Y.

Item Descriptives for LCI

The Kuder-Richardson 20 formula was used to calculate internal consistency estimates on the LCI item scores (true/false response). Satisfactory levels of internal consistency were obtained for both the parent version ($\alpha = .86$, $n = 84$) and youth version ($\alpha = .82$, $n = 87$). Mean corrected item-to-total correlation coefficients were .40 ($SD = .15$; median = .47; range = $-.01-.67$) and .35 ($SD = .16$; median = .46; range = $.05-.59$) for the parent and youth versions, respectively. Despite satisfactory levels of internal consistency across the entire questionnaires, several items (i.e., 7 items on LCI-P; 10 items on LCI-Y) attained item-to-total correlation coefficients below .30 (see Table II). Still, only three items had such values for both the LCI-P and LCI-Y. These items included “misses school,” “has problems getting along with family,” and “does not do chores at home.”

Participants reported several items as problem-

atic for the patient. Table II presents data regarding the percentage of participants that endorsed each item as occurring because of the child's illness *and* as upsetting the child either “pretty much” or “very much.” Six items were endorsed as such by at least 15% of the sample of parents and/or patients. These items included “misses school” (P and Y), “does not take part in school activities” (P), “is left out from activities or games with other children” (P), “does not play team sports” (P), “feels different from other children the same age” (P), and “does not like others to know about diet, medication, etc.” (P). With the exception of a few items, parents uniformly endorsed all items as more problematic than did children and adolescents.

Descriptive Statistics for Dependent Measures

Descriptive statistics were calculated for each dependent measure (see Table III). According to parent

Table III. Descriptive Statistics for Dependent Measures

Measure	<i>n</i>	<i>M</i>	<i>SD</i>	Range
Parent-report				
LCI-NID	88	1.2	2.8	0–18
LCI-ID	88	7.8	11.7	0–74
CBCL-Competence T ^a	72	43.5	10.2	22–63
CBCL-Externalizing T ^a	99	49.2	10.9	30–79
CBCL-Internalizing T ^a	99	53.2	11.8	31–85
No. of clinic visits (past 6 months)	106	5.0	7.0	0–36
No. of hospitalizations (past year)	106	1.3	2.3	0–14
Youth-report				
LCI-NID	91	2.5	4.7	0–26
LCI-ID	91	4.4	7.0	0–32
YSR-Competence T ^a	49	45.6	11.3	25–77
YSR-Externalizing T ^a	62	50.8	10.9	30–75
YSR-Internalizing T ^a	62	51.1	11.4	26–70
SPPC/A-Global Self-Worth	77	18.0	3.8	5–24
SPPC/A-Behavior	77	17.0	3.9	5–24
SPPC/A-Physical	76	15.7	4.6	5–24
SPPC/A-Social	78	16.8	3.9	6–24
SPPC/A-Scholastic	78	16.0	4.7	5–24
SPPC/A-Athletic	78	14.9	4.6	5–24
SPPA-Friendship	41	16.5	3.3	8–20
SPPA-Romantic	40	13.4	3.2	5–20
SPPA-Job	40	15.7	3.3	6–20
Teacher-report				
TRF-Externalizing T ^a	46	49.8	9.5	39–75
TRF-Internalizing T ^a	46	51.8	10.9	36–76
School absences: current year	46	20.7	16.2	2–61
School absences: last year	36	21.1	19.1	0–75
Grade point average: current year	42	2.3	1.1	0–4
Grade point average: last year	33	2.5	1.0	0–4
Medical chart review				
No. of clinic visits (past 6 months)	110	3.6	4.2	0–25
No. of hospitalizations (past year)	110	0.3	1.0	0–7

^aAll data analyses (e.g., correlational) used raw scores, as opposed to T-scores. The manuals for these measures suggest that raw scores be used in analyses because of the restricted range (i.e., reduced power) of T-scores. For the purposes of description, however, this table presents age/gender-based T-scores.

report, these children did not exhibit significant levels of problem behavior or social competence deficits as measured by the CBCL. Specifically, mean T-scores were within normal range. For the LCI, a one-sample *t* test revealed that parents indicated significantly higher levels of illness-related problems (i.e., mean LCI-ID = 7.8) than non-illness-related problems (i.e., mean LCI-NID = 1.2) ($p < .001$).

Similarly, the patients themselves denied experiencing significant behavioral or social problems as assessed by the YSR. Scores for the SPPC and SPPA were comparable to those obtained in healthy peers (e.g., Hagborg, 1993). Like their parents, the youths reported greater illness-related social problems (mean ID score = 4.4) than non-illness-related problems (mean NID score = 2.5) ($p < .001$).

According to teachers, participants did not display significant behavioral or social problems (i.e., TRF scores within normal range). The average number of school absences (i.e., 20.7 in current year; 21.1 in previous year), however, was quite substantial.

Correlational Analyses

To evaluate the relation between the different LCI scores (on both parent and youth versions), Pearson correlation coefficients were calculated. These results are displayed in Table IV. Significant correlation coefficients ($p < .001$) were obtained between like scores (i.e., LCI-P and LCI-Y NID scores; LCI-P and LCI-Y ID scores), while dissimilar scores (e.g., LCI-P NID score and LCI-P ID score) were correlated minimally. These

results support the distinction between these two types of social functioning scores.

To establish convergent and divergent validity for LCI scores, Pearson correlation coefficients were calculated between LCI scores and other relevant dependent measures. These coefficients, and their statistical significance levels, are presented in Table V. In general, as hypothesized, results indicated significant relations between LCI scores and related CBCL, YSR, and SPPC/A scores. For example, the LCI-P ID score was correlated significantly with the CBCL Social Competence and Internalizing Problem scores, as well as the SPPC/A Social Competence and Athletic Competence scores. In contrast, the LCI-P NID score correlated significantly with the Externalizing Problem score on the YSR and CBCL, the YSR Internalizing

score, and the SPPA Job Competence score. Similarly, the LCI-Y ID score was significantly correlated to the following measures: SPPC/A Global Self-Worth, SPPC/A Physical, SPPC-A Athletic, and the CBCL Internalizing scores. In general, the ID scores correlated significantly with internalizing problem, social competence (on the CBCL and SPPC/A), and other perceived competence scores, rather than externalizing problem scores. Correlations between LCI scores and grade point averages, school absences, and TRF scores were not statistically significant.

Univariate Analyses

Gender and Age Differences. To establish gender and age differences in LCI scores, a series of four ANOVAs were performed. In each analysis, an LCI score was the dependent variable, while gender (male, female) and age group (9–11, 12–14, 15–18) were the independent variables. LCI mean scores by gender and age group are presented in Table VI.

For the LCI-P, no significant findings were found for the ID score; however, a significant Gender \times Age Group interaction effect was obtained for the NID score, $F(2, 87) = 5.71, p < .01$. Tukey's HSD procedure indicated that for ages 9–11 years, males had signifi-

Table IV. Pearson Correlation Coefficients Between LCI Scores

Measure	LCI-ID (P)	LCI-NID (P)	LCI-ID (Y)	LCI-NID (Y)
LCI-ID (P)	—	-.11 (88)	.34* (73)	.05 (73)
LCI-NID (P)		—	.07 (73)	.45* (73)
LCI-ID (Y)			—	-.06 (91)
LCI-NID (Y)				—

n appears in parentheses.

* $p < .001$.

Table V. Pearson Correlation Coefficients Between LCI Scores and Other Measures

Measure	LCI-ID (P) <i>r</i> (<i>n</i>)	LCI-NID (P) <i>r</i> (<i>n</i>)	LCI-ID (Y) <i>r</i> (<i>n</i>)	LCI-NID (Y) <i>r</i> (<i>n</i>)
YSR-Social Competence	-.13 (40)	-.25 (40)	-.09 (45)	-.13 (45)
YSR-Externalizing	.15 (49)	.32* (49)	.01 (55)	.40** (55)
YSR-Internalizing	.22 (49)	.32* (49)	.26 (55)	.46** (55)
SPPC/A-Global Self Worth	-.16 (61)	-.19 (61)	-.31** (70)	-.14 (70)
SPPC/A-Behavior	.07 (62)	-.15 (62)	-.01 (69)	-.13 (69)
SPPC/A-Physical	-.17 (60)	-.02 (60)	-.39** (68)	-.03 (68)
SPPC/A-Social	-.26* (62)	-.05 (62)	-.20 (70)	-.38** (70)
SPPC/A-Scholastic	-.01 (63)	-.19 (63)	-.01 (70)	-.28* (70)
SPPC/A-Athletic	-.26* (62)	-.10 (62)	-.28* (70)	.03 (70)
SPPA-Friendship	.05 (34)	.20 (34)	.04 (35)	.15 (35)
SPPA-Romantic	-.32 (34)	-.28 (34)	-.21 (34)	-.49** (34)
SPPA-Job	.12 (34)	-.38* (34)	.00 (36)	-.61** (36)
CBCL-Social Competence	-.34** (58)	-.03 (58)	-.20 (60)	-.05 (60)
CBCL-Externalizing	.19 (77)	.29* (77)	.19 (77)	.31** (77)
CBCL-Internalizing	.65** (77)	.19 (77)	.43** (77)	.39** (77)
TRF-Externalizing	-.15 (35)	.19 (35)	.03 (35)	.02 (35)
TRF-Internalizing	-.12 (35)	.26 (35)	.03 (35)	.27 (35)
GPA-last year	.22 (22)	.17 (22)	.10 (25)	.09 (25)
GPA-current year	.19 (30)	.06 (30)	.12 (30)	.07 (30)
Absences-last year	.30 (26)	-.21 (26)	-.02 (26)	-.16 (26)
Absences-current year	.24 (33)	-.19 (33)	.19 (33)	-.21 (33)

* $p < .01$.

** $p < .001$.

Table VI. LCI Mean Scores by Gender and Age Group

Group (age)	LCI-NID (P)		LCI-NID (Y)		LCI-ID (Y)	
	<i>n</i>	<i>M (SD)</i>	<i>n</i>	<i>M (SD)</i>	<i>n</i>	<i>M (SD)</i>
8–11	27	2.2 (4.1)	30	5.0 (7.1)	30	4.3 (6.7)
12–15	30	0.9 (2.4)	31	1.7 (2.8)	31	4.7 (7.3)
16–18	31	0.6 (1.2)	30	0.8 (1.4)	30	4.1 (7.2)
Boys	48	1.5 (3.3)	51	2.0 (3.5)	51	3.3 (5.3)
8–11	12	4.2 (5.4)	12	4.9 (5.7)	12	5.3 (8.6)
12–15	16	0.4 (1.3)	18	1.4 (1.8)	18	2.4 (3.8)
16–18	20	0.8 (1.5)	21	0.8 (1.6)	21	2.8 (3.9)
Girls	40	0.8 (2.2)	40	3.1 (6.0)	40	5.9 (8.5)
8–11	15	0.6 (1.6)	18	5.0 (8.0)	18	3.7 (5.3)
12–15	14	1.4 (3.3)	13	2.2 (3.8)	13	7.9 (9.7)
16–18	11	0.3 (0.7)	9	0.8 (1.1)	9	7.2 (11.5)

LCI-NID = non-illness-related difficulties; LCI-ID = illness-related difficulties.

cantly (i.e., $p < .05$) higher scores than females. Also, for males, the youngest age group (9–11) had significantly higher scores than did the oldest age group (15–18).

On the LCI-Y questionnaire, no significant group differences were obtained for the ID score. In contrast, a significant main effect was found for age group with the NID score, $F(2, 90) = 6.48$, $p < .005$. Tukey's HSD procedure revealed that the youngest age group (9–11) had significantly higher scores than did either of the other two age groups (12–14, 15–18).

Illness Differences. To investigate whether chronic illness groups differed with respect to LCI scores, we conducted four separate one-way ANOVAs. The independent variable (i.e., disease grouping) consisted of five groups (i.e., seizure, asthma, cancer, arthritis/lupus, sickle cell disease) for which sufficient sample size existed. The "other" illness group was not included in these analyses because it was too small and heterogeneous to examine the different illnesses subsumed under it separately or gain any specific understanding of findings using the group as a whole. The dependent variable in each analysis was one of the two LCI scores (for both parent and youth reports). To assist with the interpretation of significant LCI findings, Table VII displays mean LCI scores by disease group.

For the LCI-P, no significant group differences were obtained for either score (ID or NID). In contrast, while no significant group differences were found for the LCI-Y ID score, a significant group difference was revealed for the NID score, $F(4, 69) = 6.89$, $p < .001$. Tukey's HSD analyses indicated that the group of patients with a seizure disorder reported significantly higher *non-illness*-related problems than

Table VII. LCI-NID (Youth Version) Scores by Disease Group

Group	<i>n</i>	<i>M</i>	<i>SD</i>
Seizure disorder (SZ)	19	6.2	6.7
Cancer (CA)	19	0.5	1.1
Asthma (AS)	13	1.0	1.5
Arthritis/lupus (AL)	11	0.9	1.0
Sickle cell disease (SC)	8	2.1	3.1

did children with arthritis or lupus, cancer, or asthma. To evaluate these results further, we performed a chi-square analysis in which the distribution of participants receiving special education services (for learning difficulties, behavior problems, or both) or not was contrasted for children with seizure disorders and children with other chronic health conditions. Results indicated that children with seizure disorders had a significantly higher distribution of special education classifications (special education, $n = 11$; regular education, $n = 9$) than did the other chronically ill children (special education, $n = 24$; regular education, $n = 66$), $\chi^2 [1] = 6.06$, $p < .05$).

Regression Analyses

Four separate multiple linear regression analyses were conducted to determine whether health care utilization rates predict LCI *illness-related* social difficulties. The dependent variable in each analysis was either the LCI-P or LCI-Y ID score. The independent variable or predictor, a health care utilization index, was created by summing the total number of clinic visits over the previous 6 months and total number of hospitalizations over the year prior to participation. For the first two analyses, the health care utilization

index was generated based on parent report, whereas, for the latter two analyses, the index was established through medical chart review.

Parent Report: Health Care Utilization. Health care utilization reported by parents significantly predicted the LCI-P ($R^2 = .18$; $F[1, 77] = 16.43$, $p < .001$) and LCI-Y ($R^2 = .28$; $F[1, 84] = 32.45$, $p < .001$) illness-related difficulties. The direction of the standardized beta coefficients ($\beta = .42$ for LCI-P; $\beta = .53$ for LCI-Y) suggested that as health care utilization increased, *illness-related* social difficulties also increased.

Medical Chart: Health Care Utilization. When using medical chart data as the independent variables, the regression equation for the LCI-Y was significant ($R^2 = .17$, $F[1, 87] = 17.87$, $p < .001$). In contrast, the regression equation for the LCI-P was not significant ($R^2 = .01$, $F[1, 82] = 1.06$, $p > .05$). Examination of the standardized beta coefficients again revealed that as health care utilization increased, so did illness-related social difficulties ($\beta = .42$ for LCI-Y; $\beta = .11$ for LCI-P).

Taken together, these findings support the initial validity of LCI scores, as it would be expected that a child/adolescent attending greater clinic visits or having more frequent hospitalizations would experience greater difficulties in social functioning (e.g., difficult to participate in team sports if attending clinic regularly).

Discussion

The LCI was devised to measure difficulties in social functioning of youths that result from experiencing a chronic illness. Currently available measures (e.g., CBCL) were not designed specifically for a chronically ill population. Consequently, these measures do not permit the distinction between social difficulties related to the illness versus those difficulties resulting from other factors (e.g., low income). Also, questionnaires that measure social functioning briefly as part of a larger construct (e.g., quality of life) are problematic for several reasons, such as typically having specificity to only one chronic illness condition (e.g., cancer; Pediatric Oncology Quality of Life; Goodwin, Boggs, & Graham-Pole, 1994). In contrast, the LCI was designed to be used across chronic medical conditions. Moreover, the LCI provides for the assessment of both a parent's and the patient's perspective of the youth's social functioning.

In addition to satisfactory levels of internal consistency, correlational results support the distinction between the ID and NID scores. Specifically, the parent's and youth's report of illness-related social difficulties

correlated significantly with one another, as did their report of non-illness-related social difficulties. In contrast, the ID and NID scores did not correlate significantly, either within or between informants. These findings strongly point to the distinction made between these scores, which was one of the primary purposes for developing the LCI.

One interesting finding of this study is that parents endorsed all but a few LCI items as more problematic than did youths. This finding is consistent with prior research that has demonstrated that children with chronic illness report less psychosocial and behavioral symptoms in themselves than parents do for these children and suggested that children may be repressing or denying their symptoms (e.g., Klinnert, McQuaid, McCormick, Adinoff, & Bryant, 2000). It is important to note that a child may have some social functioning difficulties in a certain area whether she perceives her social behavior in that area to be problematic or not. For example, missing school may not upset a child; however, it can be detrimental to the child's academic and social development and likely would be upsetting to others (e.g., parents and teachers). The LCI is intended to be used idiographically as well as normatively; thus, regardless of whether a child labels a certain item as problematic, the social behavior measured by the item can be targeted in intervention if deemed to be a problem for the individual child. Fortunately, the LCI gathers data from multiple informants (i.e., children and parents) rather than strictly from children, thereby enabling multiple perspectives on the child's social functioning. Multiple informant information increases the likelihood of identifying a child who may be in need of psychological treatment. Further, knowing that a child does not perceive an area of social functioning as problematic when others do is useful data to the clinician who is trying to engage the child in therapy.

Correlational results also provide support for the initial validity of the LCI scores. In particular, statistically significant correlations were obtained between LCI scores and related parent- and youth-report measures (e.g., CBCL and YSR scores). Of interest, the internalizing problem and social competence scores had the strongest relation with LCI illness-related problem scores. Still, these significant correlations were modest in strength, at best (i.e., highest correlation was .46). In contrast, LCI scores did not correlate significantly with teacher report of behavior problems, grades, or absence data. This lack of significant findings may be due to extraneous factors such as small sample size, self-selected sample (e.g., teachers who agreed to take time to complete and mail forms

may have different views of students, in general, than teachers who did not participate), or the measurement of distal variables (e.g., grade point average may not be closely related to social functioning). Nonetheless, the correlational findings, when considered in total, suggest that while the LCI has some relation to existing measures, it provides a unique perspective on children's social functioning.

Indeed, the sample, in general, obtained scores within the range of healthy peers or that of normative data as measured by the other questionnaires (e.g., CBCL, SPPC/A). Yet, in contrast, a substantial proportion of participants or their parents endorsed several LCI items as problematic and resulting from the patient's chronic health condition. Consequently, it appears that pediatric patients may be experiencing significant social difficulties (albeit limited in scope) as a result of their chronic illness, yet function within normal limits in terms of general behavior and perceived competence. These findings suggest that the LCI taps a unique aspect of the patient's social functioning, without assuming that significant levels of behavioral difficulties must coexist in order for a child/adolescent to be identified as having health-related social difficulties. Although this study did not include a quality of life (QOL) measure, it would be interesting for future research to examine whether these areas of functioning are related to social functioning, as measured by the LCI. In other words, would problems in social functioning be related to problems in other areas of daily living?

With respect to health-related variables, the LCI scores demonstrate some interesting relations. For example, some disease group differences were found in LCI *non-illness*-related problem scores, thereby suggesting that the LCI is potentially sensitive to specific disease factors. Specifically, children and adolescents with seizures obtained significantly higher NID scores than did youths with asthma, cancer, arthritis, or lupus. These findings may indicate that children with seizures have difficulties with socializing, perhaps as a result of compromised developmental status, yet they do not perceive these problems to be a direct outcome of their chronic health condition. Similarly, pediatric epilepsy has a significant relation with learning disabilities, attention deficit disorders, and behavioral disorders (e.g., Kim & Carey, 1998; Ziegler, Erba, Holden, & Dennison, 2000); therefore, the higher NID score may reflect these associated problems. Indeed, the results of our chi-square analysis support this latter conclusion.

In contrast, significant group differences did not occur for ID scores. Consequently, these results may

suggest that the LCI measures illness-related social functioning consistently across disease groups. In other words, when using the LCI, a child's social functioning would not be expected to vary as a direct function of a specific chronic condition, *per se*. Based on these results, it appears that another primary objective of this study (i.e., developing a measure that would apply across chronic illnesses) has initial support.

Health care utilization rates (i.e., clinic visits and hospitalizations) derived from parent report and from medical chart reviews significantly predicted LCI-Y *illness-related* scores, whereas, parent-reported utilization rates significantly predicted LCI-P ID scores. Inspection of all standardized beta weights revealed that patients attending a greater number of clinic visits and having a larger number of hospitalizations had higher levels of illness-related difficulties in social functioning. Perhaps the time spent attending medical visits and being hospitalized limits the youth's ability to participate in social activities (e.g., take part in team sports). Similarly, children who attend more frequent clinic appointments and who are hospitalized more often may have more severe health problems and, in turn, may experience a greater number of difficulties in social functioning. Future research needs to examine disease severity in addition to health care utilization rates to decipher their potentially unique contribution to social functioning in chronically ill children and adolescents.

Strengths of the current study are that we (1) used both youths and parents as informants, thereby including multiple perspectives of the patients' social functioning; (2) measured difficulties with social functioning that reportedly result from either illness or non-illness factors; (3) distinguished levels of social functioning that were perceived as problematic (i.e., "upset" the patient), as opposed to assuming that certain levels of activity were distressing to any given patient; and (4) assessed social functioning *among* various chronic illness groups, rather than focusing on any one or few chronic illness conditions.

In contrast, our findings were limited in that a single medical center (and thus, geographic region) was used for data collection. Related to using one medical center alone, our sample was not large enough to run a factor analysis to confirm the three factors of social functioning that we identified theoretically and had intended for subsuming individual items. Future research should attempt to recruit larger samples so that a confirmatory factor analysis could be run. Our study also is limited in that a relatively small proportion of fathers is represented in

the parent sample. Researchers should consider using innovative methods (e.g., telephone interviews) to obtain more data from fathers. Furthermore, one aspect of reliability, stability in test scores, was not investigated. Future studies using the LCI should consider these issues until additional psychometric research can support the generalizability and stability of scores. Finally, we recommend that researchers and clinicians not only be available during LCI completion to answer questions that may arise but also closely monitor participant responding on the LCI for accuracy. While a researcher always was available for questions in this study, future investigators may want to take more of an active role toward ensuring comprehension of the item format in particular, especially for younger children.

In summary, based on this initial psychometric evaluation, the LCI appears to have utility in measuring difficulties in social functioning resulting from pediatric chronic illness. The LCI may assist in identifying areas of social functioning that deserve efforts in prevention and education. If used routinely in specialty medical clinics (e.g., pediatric neurology), the LCI might help identify children and adolescents who may be at risk for clinically significant difficulties (e.g., anxiety and depression) in the future due to current problems in social functioning. We recommend that LCI scores be examined both normatively and idiographically to help identify potentially at-risk children. Finally, with the aid of future research,

the LCI may help guide the development and subsequent evaluation of interventions aimed at promoting adequate social functioning in chronically ill children and adolescents.

Acknowledgments

Christina D. Adams was a Visiting Assistant Professor in the Department of Clinical and Health Psychology at the University of Florida Health Sciences Center during the design and data collection stages of this investigation, but since has completed a substantial amount of creative work (e.g., data analyses, writing) at West Virginia University. We thank our colleagues at the University of Florida Health Sciences Center for their assistance in the development of this questionnaire. Specifically, we extend our appreciation to Suzanne Bennett Johnson, PhD, Sheila Eyberg, PhD, James Rodrigue, PhD, Stephen Boggs, PhD, and Eileen B. Fennell, PhD. We also thank all members of the medical staff for their tremendous assistance and cooperation with data collection. We thank the research assistants (at the University of Florida and at West Virginia University) who helped to gather, code, and enter data into statistical programs. Finally, we extend our greatest appreciation to the families who participated in our project.

Received January 26, 2001; accepted December 21, 2001

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