Development and Validation of the Pediatric Oncology Quality of Life Scale

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This study describes the development of a 21-item, parent report measure for assessing the quality of life (QOL) of children with cancer. The Pediatric Oncology Quality of Life Scale (POQOLS) provides a total score and three factor scores that assess physical function and role restriction, emotional distress, and reaction to current medical treatment. Internal consistency reliabilities of the total scale and the three factors were high, as was interparent agreement. In addition, POQOLS scores demonstrated good concurrent and discriminant relationships with scores on measures of adjustment hypothesized to covary with the dimensions of QOL assessed.

Twenty years ago, childhood cancer was viewed as an acute disease that typically progressed inexorably toward death. However, advances in treatment have produced dramatic changes in survival. For example, prior to the 1970s, patients with acute lymphoblastic leukemia had a median survival time of less than 1 year. Today, greater than 60% of individuals newly diagnosed with leukemia experience 5-year survival and probable cure (Copeland & van Eys, 1987). Similar improvements have been noted with Wilms’ tumor, Hodgkin’s and non-Hodgkin’s lymphoma, Ewing’s sarcoma, and osteogenic sarcoma (Monaco, 1994).

Along with these medical and surgical advances, there has been an increase in the amount of research directed toward describing the psychosocial sequelae of cancer treatment during childhood (see Stehbens, 1988, for review). Nevertheless, the effectiveness of specific medical interventions continues to be evaluated primarily by variables such as white blood cell count, indicators of tumor growth, and length of survival. For Schipper and Levitt (1985), “the net effect is that we design treatment to shrink tumors rather than to preserve and augment human function” (p. 1115). It is proposed that we need to move away from a sole emphasis on prolongation of survival and toward a broader conception of treatment evaluation that also encompasses qualitative aspects of survival. Over the past decade, there has been increasing recognition that the concept of quality of life is a measurable endpoint that may be of equal relevance to some patients as the traditional outcome variables.

Consideration of quality of life issues becomes particularly pertinent given that, with advances in medical science and technology, alternative forms of treatment for the same disease have begun to emerge. Consequently, the relative effects of different intervention strategies on a child’s quality of life becomes a question of considerable personal and social significance. To date, the differential functional effects on child adjustment of intrusive treatments such as radiation therapy, intensive chemotherapy, surgery, and bone marrow transplantation have received little empirical evaluation. The paucity of data in this area is striking given that treatments for childhood cancer differ in their intensity and their potential morbidity, and this may result in considerable qualitative variability between treatment protocols. Comparative quality of life studies could provide important data for use in medical decision making.

The importance of conducting quality of life research is exemplified in a study by Sugarbaker, Barkofsky, Rosenberg, and Gianola (1981). These investigators sought to evaluate the impact of limb sarcomas on adult patients’ quality of life. Treatment options included either amputation plus chemotherapy or limb-salvaging surgery plus radiotherapy with chemotherapy. It was hypothesized that limb-sparing procedures would greatly improve the patients’ psychosocial adaptation. The results of self-report measures of physical functioning and psychological adjustment suggested that there was little difference between the two groups, and some measures indicated that the amputation group experienced the more positive outcome. Many salvaged limbs functioned poorly, were painful, and inhibited patients socially and sexually. These results had not been anticipated and demonstrate the importance and value of conducting quality of life research.

The methodology of quality of life assessment has evolved considerably over the past decade in the adult oncology literature. Early efforts focused on the patient’s physical status. The first widely used quality of life measure was the Karnofsky Scale of Performance Status (Karnofsky & Buchenal, 1949). This scale reflected a unidimensional definition of quality of life, equating physical functioning with health status. Assessment research with adults and cancer has continued to progress, and several psychometrically sound quality of life measures have been developed (e.g., Aaronson, Bullinger, & Ahmedzai, 1988; Cella & Cherin, 1988; Schipper, Clinch, McMurray, & Levitt, 1984; Spitzer et al., 1981). These scales share a number of characteristics: They are cancer specific, addressing the unique experience of oncology patients; they are functionally oriented, focusing on day-to-day living issues as indicators of quality of life; they are multidimensional, incorporating several domains of the quality of life construct; they are clinically useful, brief,
methodological problems pertaining to the development of child-oriented measures of the construct is designing an assessment procedure that takes into account the developmental level of the child at diagnosis and developmental progress during treatment and recovery. Given the wide range of abilities across childhood and adolescence, a single self-report measure is quite difficult to construct. Younger children may be unable to comprehend the meaning of some items and may have limited abilities to discriminate different feeling states (Damon & Hart, 1982). Alternate forms of the same measure targeted at different age groups may fail to be directly comparable. The use of parent report rather than child report helps to alleviate such problems and has resulted in this strategy being adopted for well-validated child assessment tools such as the Achenbach Child Behavior Checklist (Achenbach & Edelbrock, 1983) and the Personality Inventory for Children (Wirt, Lachar, Klinedinst, & Seat, 1980). However, choice of informant (e.g., child or parent) to report child behavior and emotions can influence the results obtained because agreement between sources may vary widely (Achenbach, McConaughy, & Howell, 1987). Although studies have resulted in mixed outcomes, research comparing the relationship between child and parent report generally demonstrate that children report more problems related to emotional distress while parents report more problems related to observable, behavioral reactions (Stone & Lemanek, 1990). Kazdin, French, & Unis (1983) have suggested that the reports of varied informants regarding child adjustment be viewed as different but equally valid perceptions of behavior. Similarly, it is believed that the parent can be a suitable respondent and can provide reliable, valid information regarding the child's life quality (Boggs et al., 1991; Mulhern et al., 1989). A measure that uses a parent informant and that contains items applicable to both children and adolescents might better facilitate comparisons of children across the age range than multiple measures designed for child report at different age levels.

The purpose of the present study was to develop and validate the Pediatric Oncology Quality of Life Scale (POQOLS). An expert panel made up of children with cancer, their parents, and health care professionals were asked to identify the most salient dimensions underlying the quality of life construct. The information generated from these sources was used to construct an item pool. These items were reduced in number and modified on the basis of factor analysis. The resulting measure was then analyzed for reliability and validity.

Method

Phase 1: Item Generation

Participants

Patients and families. Twenty parents of children with cancer attending outpatient clinics, 20 parents whose children were hospitalized on inpatient medical units for treatment of cancer, 10 adolescents with cancer (ages 13 to 17 years), and 10 younger children with cancer (ages 6 to 10 years) were approached individually by one of the researchers, and the purpose of the study was thoroughly explained. Parents were asked to generate written statements of how their child's life had been affected by the disease experience and to provide specific behavioral indicators of these effects. Similar input was obtained from adolescents, but younger children were asked only to provide verbal responses relating to both "the bad and the good things" that they had experienced about having cancer.

Health care professionals. A group of health care professionals involved in the delivery of services to children with cancer were also asked to delineate aspects of a child's life that are affected by the cancer experience. The group included two pediatric oncologists, one inpatient pediatric oncology nursing coordinator, two outpatient pediatric oncology nurses, two inpatient pediatric oncology nurses, two bone marrow transplant unit nurses, one social worker, one pediatric psychologist, one graduate student in pediatric psychology, one child life worker, one teacher, and one hospital chaplain. Professionals provided the information to the researcher in a written format.

Settings

This phase of the study was conducted in the outpatient clinic of the Division of Pediatric Oncology and Hematology, University of Florida, and on inpatient medical units at Shands Hospital, University of Florida. All health care professionals were associated with the University of Florida.

Phase 2: Item Selection

Common domains of the quality of life of children with cancer identified by participants during the Phase 1 survey were identified and items suggested by respondents relating to these domains were listed. The most frequently identified items from each group of respondents (children, parents, health care professionals) were retained. Forty-four items were selected for inclusion.

Items were constructed so that responses were made on a 7-point Likert scale with anchor points labeled from never to very frequently. Fifty percent of the items were negatively phrased to discourage response sets (Comrey, 1988). Scoring was reversed on these items so that a high total score represented a poorer quality of life. Items were phrased to rate observable behaviors rather than estimates of a child's capacity to perform certain tasks. The desired window of time for assessment was determined to be 2 weeks because treatment protocols at outpatient clinics commonly require 2-week return visits during the most active phases of treatment. The 7-point Likert scales therefore reflected the frequency of observable behaviors over a 2-week period.

Phase 3: First-Generation Measure

Participants and Settings

The first-generation quality of life measure was administered to 210 parents of children with cancer. Parents were recruited in outpatient pediatric oncology clinics and inpatient medical units at the University of Florida; Nemours Children's Clinic, Jacksonville, Florida; and All Children's Hospital, St. Petersburg, Florida.

The mean age of the children was 9.8 years (SD = 4.1), and the mean grade level was 4.3 (SD = 3.8). Family income was rectangularly distributed with each of five income groups being equally represented (below $10,000; $10,000 to $20,000; $20,000 to $30,000; $30,000 to $45,000; and above $45,000). Thirty percent of the children had been diagnosed within 6 months, 43% within 1 year, 70% within 2 years, and 94% within 5 years. Fifty-nine percent of the children were male while 41% were female. Seventy-seven percent...
of the children were outpatients, and 23% were inpatients. Sixty-two percent of the children had a diagnosis of leukemia, 15% had diagnoses of sarcoma (osteogenic or Ewing's), and 6% were diagnosed with Hodgkin's disease. The remainder had received a variety of different diagnoses including Wilm's Tumor, neuroblastoma, and Burkett's lymphoma.

Analyses

Factor analysis used the common factor model rather than the full component model, as noncommon factor variance was assumed to exist. Principal factors were extracted from the correlation matrix, and communality estimates were placed in the diagonal. Gorsuch (1974) suggested that the largest correlation without regard to sign that each variable has with any other variable in the matrix provides an appropriate communality estimate. The square of the communality was thus a lower bound estimate for the amount of variance attributable to a factor defined by the correlated variables. Factor rotation was conducted using the varimax–promax sequence.

An item analysis examined the correlations between individual items and the total quality of life score (minus the item under consideration). Items with low item-total score correlations were not retained for the second-generation questionnaire.

Phase 4: Second-Generation Measure (POQOLS)

A 21-item, second-generation questionnaire was then administered to a new sample of parents of children with cancer. The purpose of this administration was to examine the stability of the factor structure of the measure and to explore the measure's reliability and validity.

Participants and Settings

The POQOLS was administered to 107 parents of children with cancer at the outpatient pediatric oncology departments and inpatient medical units at Emory University (Atlanta) and the University of Florida.

The mean age of the children was 9.5 years (SD = 3.9), and mean grade level was 4.1 (SD = 3.9). Family income was rectangularly distributed across all five income groups. Twenty-two percent of the children had been diagnosed within 6 months, 37% within 1 year, 60% within 2 years, and 86% within 5 years. Sixty-three percent of the children were male, and 37% were female. Eighty-two percent were outpatients, and 18% were inpatients. Seventy-one percent of the children had a diagnosis of leukemia, 19% had a diagnosis of sarcoma (including Ewing's, osteogenic, and rhabdomyosarcoma), and the remainder of the sample had various other diagnoses (e.g., Wilm's tumor, Hodgkin's disease, medulloblastoma).

Analyses

The identical factor analysis procedures that were used for the first-generation measure were replicated with the second-generation questionnaire.

Reliability

Internal consistency of the measure was assessed by coefficient alpha. Additionally, interrater reliability between mothers and fathers was examined by asking both parents of the same child to complete the measure without discussing their answers. The investigator remained with the parents until the measure was completed to ensure the independence of the ratings.

Validity

Concurrent validity. The validity of the POQOLS was explored by examining the correlations between scores on the identified factors and scores on other measures hypothesized to be related to these factors. The following measures were selected:

The Play Performance Scale for Children (PPSC; Lansky, List, Lansky, Cohen, & Sinks, 1985) was developed as a childhood modification of the Karnofsky Performance Scale (Karnofsky & Buchenal, 1949). A single rating on a 10-point scale is provided by a parent. The scale reflects the extent to which the patient experiences restrictions in physical activity. Lansky, List, Lansky, Ritter-Sterr, and Miller (1987) reported mother–father interrater reliability of .71, correlations with global functional ratings by nurses of .75, and significantly lower ratings for inpatients than for outpatients.

The Child Behavior Checklist (CBCL; Achenbach & Edelbrock, 1983) provides an assessment of behavior problems of children aged 4 through 16 years as reported by their parents. It assesses many symptom categories and provides an index of general adjustment (total score), an internalizing problem score, and an externalizing problem score. Interrater reliability has been reported at .985 for total behavior problems. One-week and 3-month test–retest reliabilities for total behavior problem scores were .952 and .838, respectively. Validity studies have shown that the behavior problem scales are effective in discriminating among known groups (Achenbach & Edelbrock, 1983).

The Reynolds Adolescent Depression Scale (RADS; Reynolds, 1987) is a 30-item self-report measure intended to assess the severity of depressive symptomatology in adolescents aged 13–18 years. Internal consistency as measured by coefficient alpha has been calculated as r = .93. Split-half reliability has been reported as r = .91. Concurrent validity was demonstrated by a correlation of r = .76 with the Child Depression Inventory (Kovacs, 1979).

Discriminant validity. Discriminant validity was assessed by comparing quality of life scores for children in remission with those of children recently diagnosed and undergoing active treatment. Mean quality of life scores were compared using one-way analyses of variance (ANOVAS).

Results

First-Generation Measure

Scores on positively phrased items were reversed so that a meaningful total quality of life score could be calculated for each child. A low score reflected excellent quality of life, and a high score reflected a poor quality of life. The scores ranged from 43 to 233 with a mean of 113.2 (SD = 35.3). Item-total correlations were calculated for each item, and items with low item-total correlations (r < .3) were eliminated.

Factor analytic procedures were conducted using 36 of the original items. On the basis of scree plot criteria, a seven-factor solution was examined. The seven-factor solution accounted for 74% of the total variance. Factors 5, 6, and 7 were discarded, as they were largely uninterpretable. Varimax rotation produced a four-factor solution that accounted for 62% of the total variance.

Orthogonal and oblique solutions were contrasted. The four-factor oblique solution identified the same factors and generally inflated the loadings of those items that contributed most to each factor. The four-factor orthogonal solution was preferred over the oblique solution, as the latter accounted for only 57% of the total variance.

Interpretation of factors involved examining the content of those items that contributed the highest loadings to each factor.
Factor 1 was identified as being sensitive to restrictions in physical functioning and ability to maintain normal physical routine. Factor 2 was identified as a measure of emotional distress (e.g., fear, withdrawal). Factor 3 was described as a measure of externalizing behavior (e.g., tantrums, noncompliance). Factor 4 appeared to be a measure of response to current medical treatment (e.g., nausea, vomiting, pain).

Items that did not contribute significant loadings to any factor were eliminated. In addition, if 2 items expressed highly similar ideas, then 1 item was discarded. The remaining 21 items were retained for the second-generation measure.

Second-Generation Measure (POQOLS)

POQOLS scores ranged from 24 to 121 (M = 65.2; SD = 20.3). The scores were normally distributed.

Factor Analysis

The second-generation measure was factor analyzed using principal factors as the method of extraction. Factor 1 had an eigenvalue of 5.27, Factor 2 had an eigenvalue of 2.67, and Factor 3 had an eigenvalue of .92. A three-factor solution was considered, as the third factor approached an eigenvalue of 1 and appeared highly interpretable.

The three-factor solution accounted for 80% of the total variance. Varimax and promax rotations were performed, but again the varimax solution was retained, as it accounted for slightly more variance. The three-factor varimax orthogonal solution is presented in Table 1.

Factors were interpreted on the basis of the content of the items that produced the highest loadings. Factor 1 is best represented by items 4, 7, 10, and 15 and moderate loadings on Items 14, 5, 16, and 21. Factor 1 was again interpreted in the same manner as for the first-generation measure. The items appear to be a measure of physical functioning and restriction from normal activity. Factor 2 was also interpreted in a similar manner to the first-generation measure, that is, as an indicator of emotional distress. The externalizing items that comprised Factor 3 in the first-generation measure were pooled together with the internalizing items to create a general emotionality factor in this measure.

Scores on Factor 1 were highest for Group 3 (M = 23.4, SD = 9.8) and Group 2 (M = 24.6, SD = 11.9) and for Factor 2, Group 2 (M = 22.4, SD = 8.8) had a higher mean score than either Group 1 (M = 20.3, SD = 7.4) or Group 3 (M = 16.5, SD = 6.4). No other comparisons were significant.

Reliability

Two methods of assessing the reliability of the POQOLS were used. First, coefficient alpha was calculated as .85 for the total measure. Coefficient alpha was also calculated for the total scores on each factor. Internal consistency reliability coefficients were .87, .79, and .68 for Factors 1, 2, and 3, respectively. Second, interrater reliability between mothers and fathers was calculated for a sample of 15 children. Pearson product–moment correlation for the total quality of life score was .87. The interrater reliability values were .91, .87, and .75 for Factors 1, 2, and 3, respectively.

Validity Measures

Along with the administration of the POQOLS, 40 parents rated their child's behavioral adjustment on the CBCL, 50 parents rated their child's physical functioning on the PPSC, and 15 adolescents completed the RADS. These participants were chosen consecutively on the basis of their willingness to complete additional measures during their clinic visits or hospitalizations. There were no differences in the demographic characteristics of this subsample and the larger sample.

It was hypothesized that scores on Factor 1 would correlate most highly with scores on the PPSC and that scores on Factor 2 would correlate most highly with the total behavior problem score of the CBCL and with scores on the RADS. It was expected that scores on Factor 3 would correlate moderately with scores on the CBCL.

Factor scores on the POQOLS were generated for each individual, and Pearson product–moment correlations were calculated between the factor scores and the scores on the validation measures. The total behavior problem T score on the CBCL was used as the general measure of perceived emotional distress. Total internalizing and externalizing T scores on the CBCL were also used. Both the PPSC and the RADS generate only one score. These correlations are reported in Table 2.

In addition, the relationship between time since diagnosis and scores on Factor 3 was examined for all children. It was hypothesized that children who were recently diagnosed and therefore receiving active treatment would score higher on this factor than children who were no longer in active treatment status. Factor 3 correlated negatively with time since diagnosis, r = -.275 (p < .008).

Next, the children were divided into two groups on the basis of time since diagnosis to examine the discriminant ability of the measure. Children who had been diagnosed more than 30 months previously, who were no longer in the acute treatment...
Table 1
Three-Factor Varimax Solution: Second-Generation Measure
(Pediatric Oncology Quality of Life Scale)

<table>
<thead>
<tr>
<th>Item</th>
<th>Factor 1</th>
<th>Factor 2</th>
<th>Factor 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child has anger outbursts</td>
<td>-.098</td>
<td>.724</td>
<td>-.064</td>
</tr>
<tr>
<td>2. My child has expressed fear about the disease and its treatment</td>
<td>.148</td>
<td>.525</td>
<td>.186</td>
</tr>
<tr>
<td>3. My child has been sad</td>
<td>.032</td>
<td>.681</td>
<td>.378</td>
</tr>
<tr>
<td>4. My child has been able to participate in recreational activities (sports, games, etc.)</td>
<td>.769</td>
<td>.008</td>
<td>.195</td>
</tr>
<tr>
<td>5. My child has had less energy and has been easily tired out</td>
<td>.514</td>
<td>.304</td>
<td>.136</td>
</tr>
<tr>
<td>6. My child has required active medical treatment</td>
<td>.106</td>
<td>.067</td>
<td>.447</td>
</tr>
<tr>
<td>7. My child has been able to interact/play with friends completely normally</td>
<td>.778</td>
<td>.030</td>
<td>.141</td>
</tr>
<tr>
<td>8. My child has complained of pain from medical procedures</td>
<td>.017</td>
<td>.264</td>
<td>.635</td>
</tr>
<tr>
<td>9. My child has been embarrassed about physical changes (hair loss, weight change, etc.)</td>
<td>.204</td>
<td>.356</td>
<td>.283</td>
</tr>
<tr>
<td>10. My child has been physically capable of performing as usual</td>
<td>.811</td>
<td>.012</td>
<td>.138</td>
</tr>
<tr>
<td>11. My child has had trouble sleeping</td>
<td>.190</td>
<td>.251</td>
<td>.302</td>
</tr>
<tr>
<td>12. My child has complained about physical pain from his/her cancer</td>
<td>.149</td>
<td>.181</td>
<td>.583</td>
</tr>
<tr>
<td>13. My child has been bothered by other people treating him/her differently</td>
<td>.093</td>
<td>.402</td>
<td>.247</td>
</tr>
<tr>
<td>14. My child has been satisfied with his/her recent physical activity</td>
<td>.546</td>
<td>.033</td>
<td>.048</td>
</tr>
<tr>
<td>15. My child has played/visited with friends</td>
<td>.800</td>
<td>.009</td>
<td>.018</td>
</tr>
<tr>
<td>16. My child has been able to attend school</td>
<td>.586</td>
<td>.010</td>
<td>.414</td>
</tr>
<tr>
<td>17. My child has demanded more help with daily tasks than he/she needs</td>
<td>.056</td>
<td>.554</td>
<td>.215</td>
</tr>
<tr>
<td>18. My child has been hostile</td>
<td>.046</td>
<td>.807</td>
<td>.119</td>
</tr>
<tr>
<td>19. My child has spent time during the day resting</td>
<td>.392</td>
<td>.093</td>
<td>.214</td>
</tr>
<tr>
<td>20. My child has had nausea or vomiting due to treatment</td>
<td>.213</td>
<td>.173</td>
<td>.498</td>
</tr>
<tr>
<td>21. My child has needed extra help with daily living skills</td>
<td>.467</td>
<td>.296</td>
<td>.065</td>
</tr>
</tbody>
</table>

Note: Numbers in boldface represent items with highest loadings on each factor.

Discussion
This study has addressed the development and validation of a quality of life measure for use with pediatric oncology patients. Despite great interest in the issue of quality of life, to date no validated tool has been developed for the assessment of this construct for children with cancer.

Internal consistency and interrater reliability were used as indices of reliability. Coefficient alpha examines whether items within a measure contribute significantly to the overall score by exploring the correlations between each item and the total score of the measure. The coefficient alpha of the total scale (r = .85) suggests high correlations between individual items and the...
Table 2
Correlations Between Factor Scores and Scores on Validity Measures

<table>
<thead>
<tr>
<th>Factor</th>
<th>PPSC*</th>
<th>CBCL-Tb</th>
<th>CBCL-Ib</th>
<th>CBCL-Eb</th>
<th>RADSb</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.60*</td>
<td>.19</td>
<td>.20</td>
<td>.16</td>
<td>.07</td>
</tr>
<tr>
<td>2</td>
<td>.06</td>
<td>.67*</td>
<td>.68*</td>
<td>.67*</td>
<td>.60</td>
</tr>
<tr>
<td>3</td>
<td>-.30</td>
<td>.41</td>
<td>.46</td>
<td>.51*</td>
<td>.37</td>
</tr>
</tbody>
</table>

Note. Alpha was set at $p < .003$ to reduce Type-I errors (Bonferroni correction). PPSC = Play Performance Scale for Children; CBCL-I = Child Behavior Checklist—Internalizing Scale; CBCL-E = Child Behavior Checklist—Externalizing Scale; RADS = Reynolds Adolescent Depression Scale.

*p < .001.

overall score. Cella and Tulsy (1990) suggested that, because quality of life is not hypothesized to be a unidimensional construct, a high internal consistency might not be necessary to conclude reliability of measurement. The high coefficient alpha in this instance indicates that the multidimensional nature of the construct need not compromise internal consistency. With regard to the relationship between items within each factor and the total score for that factor, Factor 1, restriction in physical functioning and ability to maintain normal routine, has the highest internal consistency, while Factor 3, response to active medical treatment, has the lowest internal consistency. The lower internal consistency of Factor 3 may in part be attributable to the smaller number of items that contribute to the overall score for this factor.

Interrater reliability was also found to be high ($r = .89$) for a sample of 15 couples assessing their child each independent of the other. This is a promising statistic given that the scale uses parents’ ratings to assess the quality of life of their children. Because the number of parent dyads available for this analysis was small, further examination of the agreement between parents on this measure is warranted. A larger sample of couples rating their child’s quality of life could provide a meaningful analysis of interrater agreement for each item rather than only for the overall scores of the scale and the three factors. This would permit further evaluation and refinement of the objectivity of the individual items.

Correlations reported in Table 2 between the factor scores and the scores on validity measures support the interpretations of the three factors. Factor 1 was interpreted as a measure of restrictions in physical functioning and ability to maintain normal routine. This factor correlated significantly with the PPSC scores but not with the scores on the three CBCL scales or the RADS. This result suggests that functional performance is significantly associated with scores on this factor. The PPSC has been criticized by Mulhern et al. (1989) because of an artificially low ceiling of performance. The truncated ceiling may result in artificially low correlations, although it is difficult to assess to what extent this limitation of the PPSC precludes convergent validity determinations.

The CBCL total, internalizing, and externalizing scores correlated significantly with Factor 2 scores, supporting the interpretation of this factor as an indicator of general emotional adjustment. Factor 2 (POQOLS) represents a collapse of Factor 2 (internalizing behaviors) and Factor 3 (externalizing behaviors) of the first-generation measure. The collapse of these two factors from the first-generation measure may be accounted for by frequent co-occurrence of both internalizing and externalizing problems. High correlations between measures of conduct problem behaviors and internalizing behaviors have been reported by previous investigators (Achenbach & Edelbrock, 1983; Boggs, Eyberg, & Reynolds, 1990).

The nonsignificant but high correlation between Factor 2 scores and the RADS scores appears attributable to the small sample size of adolescents completing the measure ($n = 15$). It is possible that a larger sample of adolescents would have provided more encouraging results. Nevertheless, it is a hopeful outcome demonstrating possible concurrence between adolescent self-report and parent report of emotional symptomatology.

Factor 3 scores correlated significantly with the externalizing scores on the CBCL and with time since diagnosis. Correlations between scores on Factor 3, the PPSC scores, and the CBCL internalizing and total scores approached significance. This suggests that the scores on this factor, which were believed to indicate frequency of nausea, vomiting, and pain, covary with the behavioral disruption and restrictions of activity often seen in the active phase of treatment. Additionally, scores on Factor 3 tended to be higher for those children who were recently diagnosed and who were more likely therefore to be experiencing the physical symptoms of cancer and its medical treatment. Taken together, these results support the interpretation of Factor 3 as an indicator of physical discomfort that may be associated with early phases of treatment.

Aaronson and Beckman (1987) defined four quality of life domains consisting of (a) functional status (self-care, mobility, physical activities, role activities), (b) disease-related and treatment-related physical symptoms (pain, nausea), (c) psychological functioning (anxiety, depression), and (d) social functioning. Factor 1 of this pediatric measure, restriction in physical functioning and ability to maintain normal routine, is directly comparable to these authors’ functional status and social functioning domains. Factor 2, general emotionality, is directly related to the psychological functioning domain and Factor 3, response to active medical treatment, is comparable to the disease- and treatment-related physical symptoms domain. The high degree of concordance between the factors on the POQOLS and the
The discriminant validity analyses revealed a significant difference in total scores, Factor 1 scores, and Factor 3 scores between two groups of children differentiated on time since diagnosis. These findings indicate that recently diagnosed children in this study were rated on POQOLS as having lower overall quality of life, poorer physical functioning, and more physical discomfort than children who were diagnosed more than 30 months previously, who were in remission, and who were no longer receiving active medical treatment. Contrary to our hypothesis, there was no significant difference on Factor 2, indicating that parent ratings of emotional adjustment were similar for newly diagnosed children and children in remission. It is possible that a child’s emotional adjustment as measured by Factor 2 is not as closely associated with changes in the child’s health status as the total score and Factors 1 and 3 scores, but may be more related to other variables such as adjustment prior to disease onset. Alternatively, it is possible that emotional reactions co-occurring with cancer and its treatment may remain long after the acute treatment phase. Further study of the relationship between this factor score, time since diagnosis, and premorbid adjustment is necessary to clarify this finding.

Because POQOLS was designed for use with parents of children from preschool age through adolescence, developmental differences in scores on the measure were examined. Comparison of mean scores for three age groups (7 years and under, 8–12 years, and 13 years and over) revealed differences on Factors 1 and 2, but not on total scores or Factor 3 scores. Parents of children over 13 years of age tended to rate their teenagers as more negatively affected by physical functioning and restriction from normal routine (Factor 1) than parents of younger children in the two other age groups. In addition, parents of children between the ages of 8 and 12 years tended to rate their children as having more difficulty with emotional adjustment (Factor 2) than the parents of children in the other two groups. It is likely that children at different ages may show their distress in different ways. Analyses of such age differences with large numbers of individuals will be important for refining our understanding of the influence of development on the different dimensions of the quality of life of children with cancer.

The POQOLS marks an initial attempt at introducing assessment of the quality of life construct for children with cancer. Results of reliability and validity assessments provide preliminary support for the psychometric adequacy of the measure and suggest that POQOLS scores demonstrated adequate convergent and discriminant relationships when contrasted with scores from appropriate measures. Furthermore, with the exception of Factor 2 scores, the POQOLS scores appeared to be able to discriminate as predicted between two groups of children differentiated on the basis of time since diagnosis.

In addition, the measure developed in this study has many of the important characteristics of a pediatric cancer quality of life measure as suggested by Mulhern et al. (1989): It is sensitive to common functional problems of children with cancer; it is reliable and valid for the population; it is brief, simple, easy to administer and repeatable; and it assesses the frequency of problems rather than estimates of the child’s capacity. As suggested by Mulhern et al. (1989), there is a need to gather normative data for children at various stages during and after treatment to assist interpretation of quality of life scores.

Although these results are promising, further examination of the measure’s relationship to the quality of life of children with cancer is necessary. For example, the use of a third-party respondent to evaluate a child’s adjustment to cancer and its treatment may result in different conclusions than if the child’s own perceptions were assessed. In fact, the correlation between parent report on Factor 2 scores (emotional responding) and adolescent self-report of depressive symptoms was high (r = .60) but did not reach significance. Mulhern, Fairclough, Smith, and Douglas (1992) found interrater reliabilities between mothers’, nurses’, and children’s ratings of depression in children with cancer to be low and that classification of the children was dependent on the informant and assessment method used. Further study of the relationships between this parent report measure and child self-report across the domains of quality of life is recommended. Multiple informant assessment of children’s behavior has frequently been found necessary to develop a comprehensive overview of a child’s psychological functioning (La Greca, 1990).

Quality of life assessment in pediatric oncology is an important addition to the study of treatment of childhood cancer. Measures of quality of life may generate clinical information that will assist guardians, parents, and health professionals to make informed choices among therapeutic alternatives. Additionally, such measures can assist with identifying children with an increased risk for functional problems. Consequently, early interventions can be targeted toward the at-risk population. As collaboration between psychologists and oncologists increases, broader conceptions of treatment evaluation become more possible. Inclusion of quality of life assessment in the clinical trials process is an important step in the movement toward biopsychosocial conceptions of health status (Engel, 1978).

References


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