Validation of an “In the Moment” Pediatric Quality of Life Scale for Hospitalized Children

Nancy A. Ryan-Wenger, PhD, RN, CPNP, FAAN
Nationwide Children’s Hospital, Columbus, OH

Aricka Kesic-Sellers, MSN, RN, CNP
Psychiatric Mental Health Nurse Practitioner, Fairlawn, OH

James W. Varni, PhD
Texas A&M University, TX
Disclosures

The authors have no disclosures or conflicts of interest related to this presentation.

Objectives

1. Describe the need for a brief quality of life instrument for hospitalized children.
2. Evaluate the psychometric properties of the PedsQL-IM scale.
Health-Related Quality of Life

• A measure of the impact of illness and the outcomes of treatment from the individual’s perspective

• Included as an outcome measure in most intervention studies
PedsQL™

• Based on a model for measurement of health-related quality of life in pediatric populations

• Pediatric Quality of Life (PedsQL™) Inventory Generic Core Scale (Varni, et al., 1999)

• Generic – applies to all children and adolescents (ages 5 to 18 years)

• Retrospective assessment of 23 items during the past month
**Hospitalized Children**

- Children’s perceptions of their illness, symptoms, and treatment change daily, hourly, or momentarily

- A brief, in-the-moment, health-related quality of life measure for hospitalized children is needed

- Use for assessment, and to evaluate quality of care and treatment outcomes
Ecological Momentary Assessment Theory

A method of assessing a person’s behavior, feelings, or symptoms in his or her natural environment at that specific moment in time (Hufford & Shiffman, 2001)
PedsQL™ Present Functioning Visual Analog Scale (VAS)

- Measures 6 “in the moment” quality of life variables (Sherman, et al., 2006)

- I feel….
  - Angry
  - Worried about what will happen to me
  - Afraid or scared
  - Sad or blue
  - Pain or hurt
  - Tired
Scores for each item are summed and averaged
- Total Symptom Score (all 6 items)
- Emotional Distress Summary Score (angry, worried, afraid, sad)
Limitations of PedsQL-VAS

High scores indicate *low* quality of life

It is *not feasible* in practice or research to measure, sum, and average the length of six 100 mm lines.
Pediatric Quality of Life “In the Moment” scale (PedsQL-IM)

- Designed a large research study (N=500) of hospitalized children’s perceptions of the quality of their nursing care (Ryan-Wenger & Gardner, 2012)

- Collaborated with James Varni, PhD to change the VAS to an ordinal scale with five response options for each item

  1 = not at all  
  2 = a little bit  
  3 = somewhat  
  4 = quite a bit  
  5 = very much
Purpose

• To evaluate the reliability & construct validity of the PedsQL-IM

Design

• Secondary analysis
• Cross-sectional
• Descriptive
Setting

- 450-bed freestanding children’s hospital

Sampling Plan

- Hospitalized
- Ages 6 to 21 years
- Developmental age ≥6 years
- English-speaking
Procedure

- IRB approval – minimum risk
- Consent & assent

- Trained research assistants
- Individual interviews with the children
- Forms completed by children or items read to children by RA
- Certificate of Appreciation
Measures

- Demographics
- # invasive procedures prior to interview
- # of previous hospitalizations
- Length of hospital stay at time of interview

- Construct validity
  - PedsQL-IM
  - Revised Children’s Anxiety & Depression Scale (RCADS)
Revised Children’s Anxiety & Depression Scale (RCADS)

47 items on ordinal scale
- 0 = never
- 1 = sometimes
- 2 = often
- 3 = always

Raw scores converted to T-scores based on age and grade in school
- Normal <65
- Borderline 65 to 69
- Clinical ≥70

Scales 0 to 100
- Total anxiety & depression
- Total anxiety
- Separation anxiety
- Social phobia
- Generalized anxiety
- Panic disorder
- Obsessive-compulsive
- Major depression
Results

N = 410 children & adolescents
n = 204 females
n = 206 males

Mean age = 13.85 ± 3.58
Median age = 14 (IQR 11, 15)

Race
- White n=298 (72.7%)
- Black n=84 (20.5%)
- Other/mixed n=28 (6.8%)

Previous hospitalization:
n=268 (65.4%)
PedsQL-IM Scores

Percent

0 10 20 30 40 50 60 70 80 90 100

Angry Afraid Sad Worried Pain Tired

21.5 28.5 36.8 58 59.3 77.3
RCADS Scores
Reliability

Domain Sampling Theory

- Internal consistency: coefficient alpha (stand. Items) = .71
- Item-item correlations: $r = .319$ to $.495$ with $\geq 1$ other item
- Item-total correlations: $r = .551$ to $.689$

Classical Measurement Theory: ANOVA

- $F = 105.994$ (p<.001) between items within individuals indicates absence of a response set
- MS variance between individuals $> MS$ variance total residuals ($2.099$ vs $.806$) indicates that scores differed between individuals
Construct Validity: Principal Components Factor Analysis

<table>
<thead>
<tr>
<th>PedsQL-IM items</th>
<th>Component 1</th>
<th>Component 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel afraid or scared</td>
<td>.830</td>
<td>-.012</td>
</tr>
<tr>
<td>I feel sad or blue</td>
<td>.569</td>
<td>.412</td>
</tr>
<tr>
<td>I feel angry</td>
<td>.434</td>
<td>.534</td>
</tr>
<tr>
<td>I worry about what will happen to me</td>
<td>.756</td>
<td>.133</td>
</tr>
<tr>
<td>I feel tired</td>
<td>.029</td>
<td>.805</td>
</tr>
<tr>
<td>I feel pain</td>
<td>.117</td>
<td>.794</td>
</tr>
</tbody>
</table>

Extraction Method: Principal Component Analysis
Rotation Method: Varimax with Kaiser Normalization
Rotation converged in 3 iterations
Correlations > .30 between PedsQL-IM items & RCADS scales (all $p < .001$)

<table>
<thead>
<tr>
<th></th>
<th>Afraid</th>
<th>Sad</th>
<th>Angry</th>
<th>Worried</th>
<th>Tired</th>
<th>Pain</th>
<th>Total Score</th>
<th>Emot. Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Separation anxiety</td>
<td></td>
<td></td>
<td></td>
<td>.347</td>
<td></td>
<td></td>
<td>.366</td>
<td>.384</td>
</tr>
<tr>
<td>Generalized anxiety</td>
<td></td>
<td></td>
<td></td>
<td>.477</td>
<td></td>
<td></td>
<td>.405</td>
<td>.403</td>
</tr>
<tr>
<td>Panic disorder</td>
<td></td>
<td></td>
<td></td>
<td>.354</td>
<td></td>
<td></td>
<td>.390</td>
<td>.341</td>
</tr>
<tr>
<td>Social phobia</td>
<td></td>
<td></td>
<td></td>
<td>.357</td>
<td></td>
<td></td>
<td>.354</td>
<td>.332</td>
</tr>
<tr>
<td>OCD</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.300</td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
<td></td>
<td>.422</td>
<td>.405</td>
<td>.318</td>
<td>.528</td>
<td>.432</td>
</tr>
<tr>
<td>Total anxiety</td>
<td></td>
<td></td>
<td></td>
<td>.447</td>
<td></td>
<td></td>
<td>.356</td>
<td>.452</td>
</tr>
<tr>
<td>Anxiety &amp; depression</td>
<td>.301</td>
<td></td>
<td></td>
<td>.464</td>
<td>.315</td>
<td></td>
<td>.494</td>
<td>.452</td>
</tr>
</tbody>
</table>
Discussion

- The 410 children in this study reflected the demographic and clinical characteristics of this large, freestanding children’s hospital.

- Nearly two-thirds of our sample had been hospitalized prior to this study, which reflects the chronicity of many childhood illnesses.

- PedsQL-IM has adequate reliability (.70 to .71), no evidence of a response set in item scores, and adequate variability in scores between subject

- Factor analysis and correlations between the PedsQL-IM and RCADS indicate strong construct validity
Discussion

• As a symptom checklist, the majority of responses are expected to be ‘not at all’ or ‘a little bit’
  – Responses of ‘somewhat’, ‘quite a bit’, or ‘very much’ should be of concern to health care providers

• “I feel worried about what will happen to me” was reported by 58% of the children
  – This item correlated from $r = .347$ to $0.477$ will all of the RCADS subscales

• “I feel sad or blue” was reported by 46.8% of the children
  – 7.5% of the children had borderline or clinical scores for depression

• “I feel pain” was reported by 28.8% of the children
  – Pain is assessed at least hourly
  – Hospital’s goal is to be a “pain-free zone”
Discussion

• “I feel afraid or scared” was reported by 28.5% of the children
  – 12.8% of the children had borderline or clinical scores on the RCADS separation anxiety subscale

• “I feel angry” was reported by 21.5% of the children
  – This symptom has not been reported in studies of hospitalized children

• Nurses and other staff do not normally ask children if they are afraid, worried about what will happen to them, sad, or angry

• Children are rarely asked about whether or not they feel tired, a physical symptom, but it was scored positively by 77.3% of the children in this study
Conclusions

• The PedsQL-IM scale should become the 6th Vital Sign
  – Measure at regular intervals during hospitalization
  – Immediate follow-up with more specific questions
  – Interventions to alleviate symptoms
  – PMH referral if “I feel sad”, “I feel angry”, or “I feel worried” scores are high

• Research is needed to evaluate the extent to which scores change over time, and their utility as a health-related quality of life outcome of care