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

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NATIONWIDE CHILDREN'S
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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
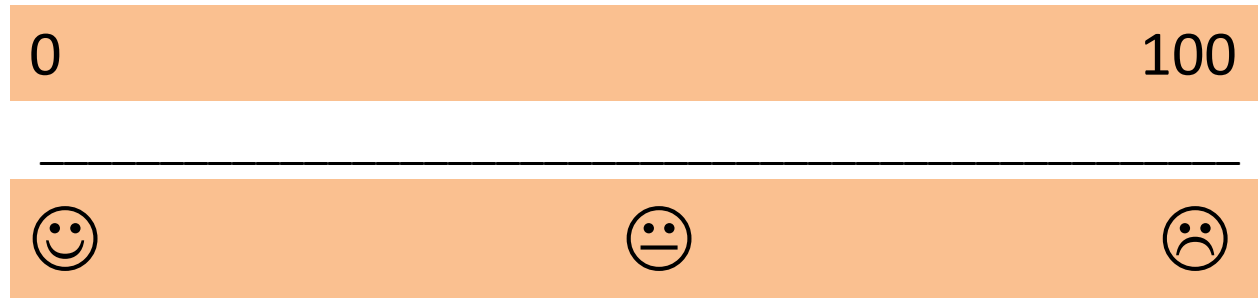 - Afraid or scared
  - Sad or blue
  - Pain or hurt
  - Tired

100 mm VAS Scale

0		100

_____

☺　　　　　　　😐　　　　　　　☹

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

0		100
☺	😐	☹

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

- 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
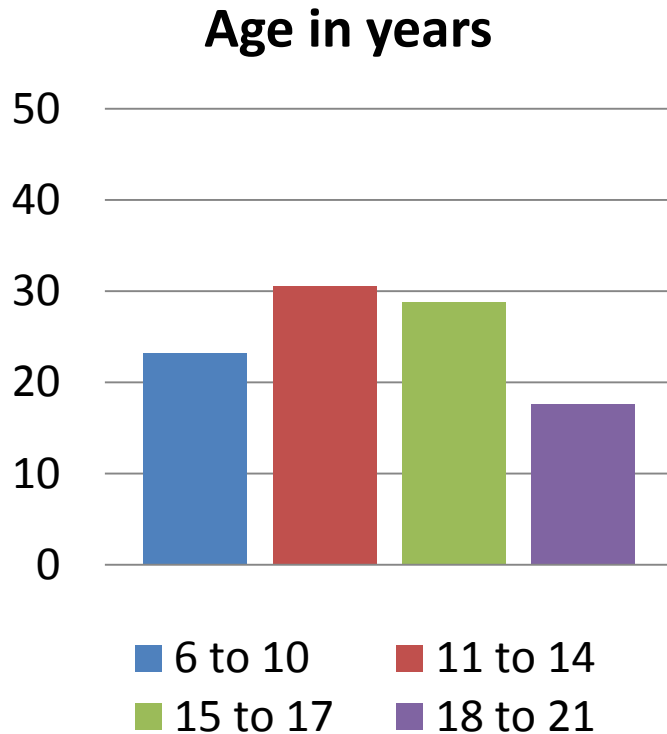- 2 = often
- 3 = always

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

Age in years

N = 410 children & adolescents

n = 204 females
n = 206 males

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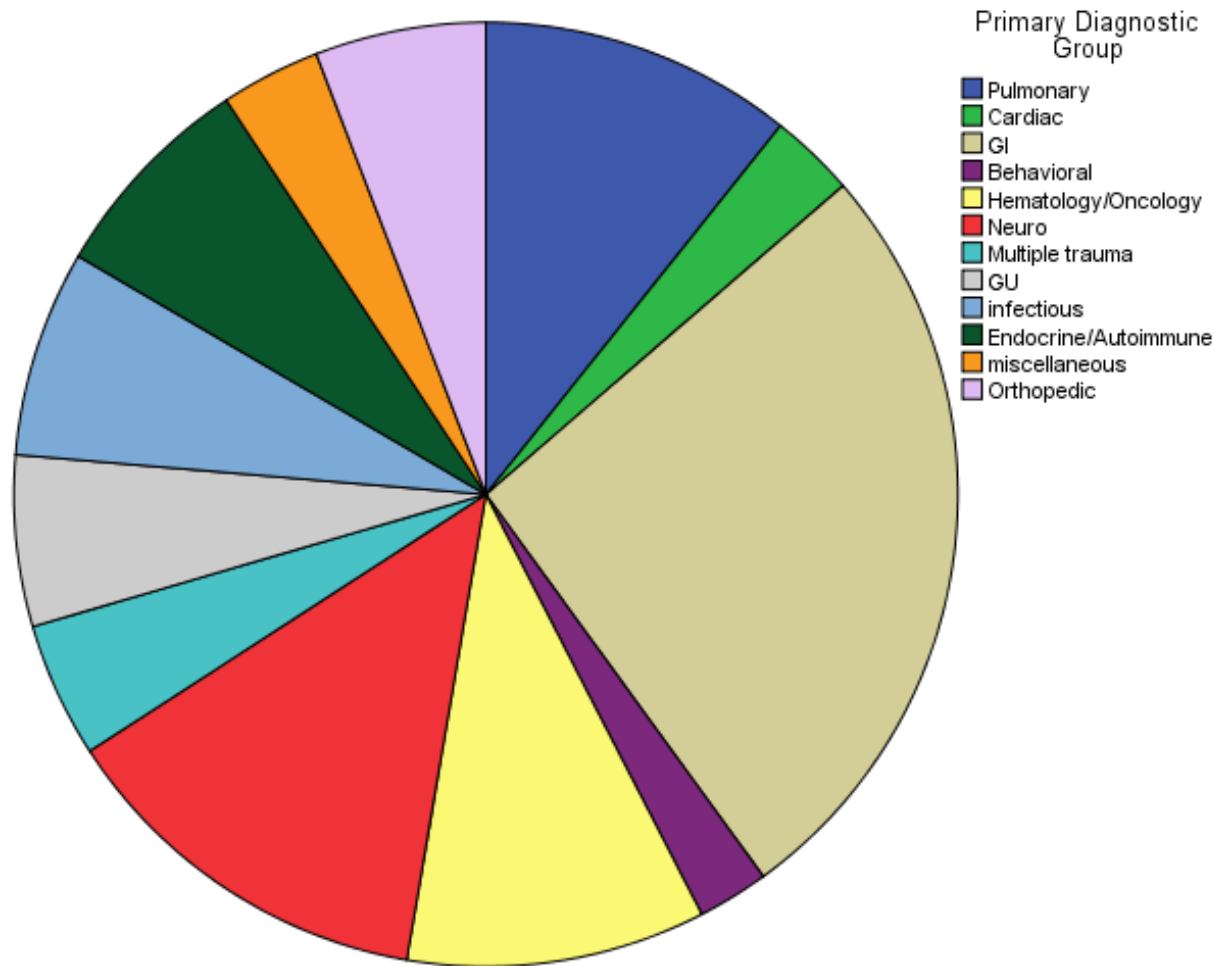Median age = 14 (IQR 11, 15)

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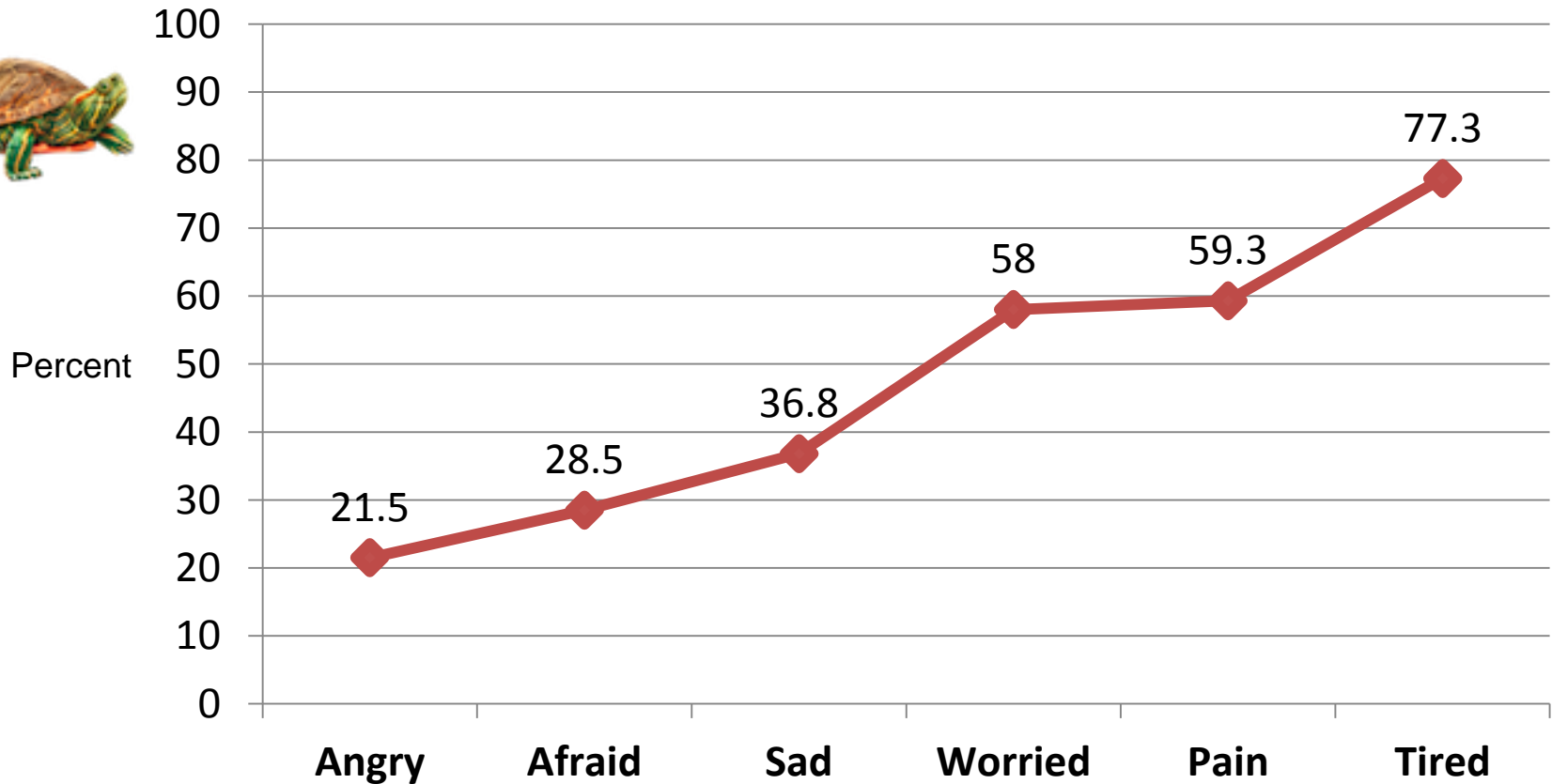 Black   n=84 (20.5%)
  Other/mixed   n=28 (6.8%)

Previous hospitalization:
n=268 (65.4%)

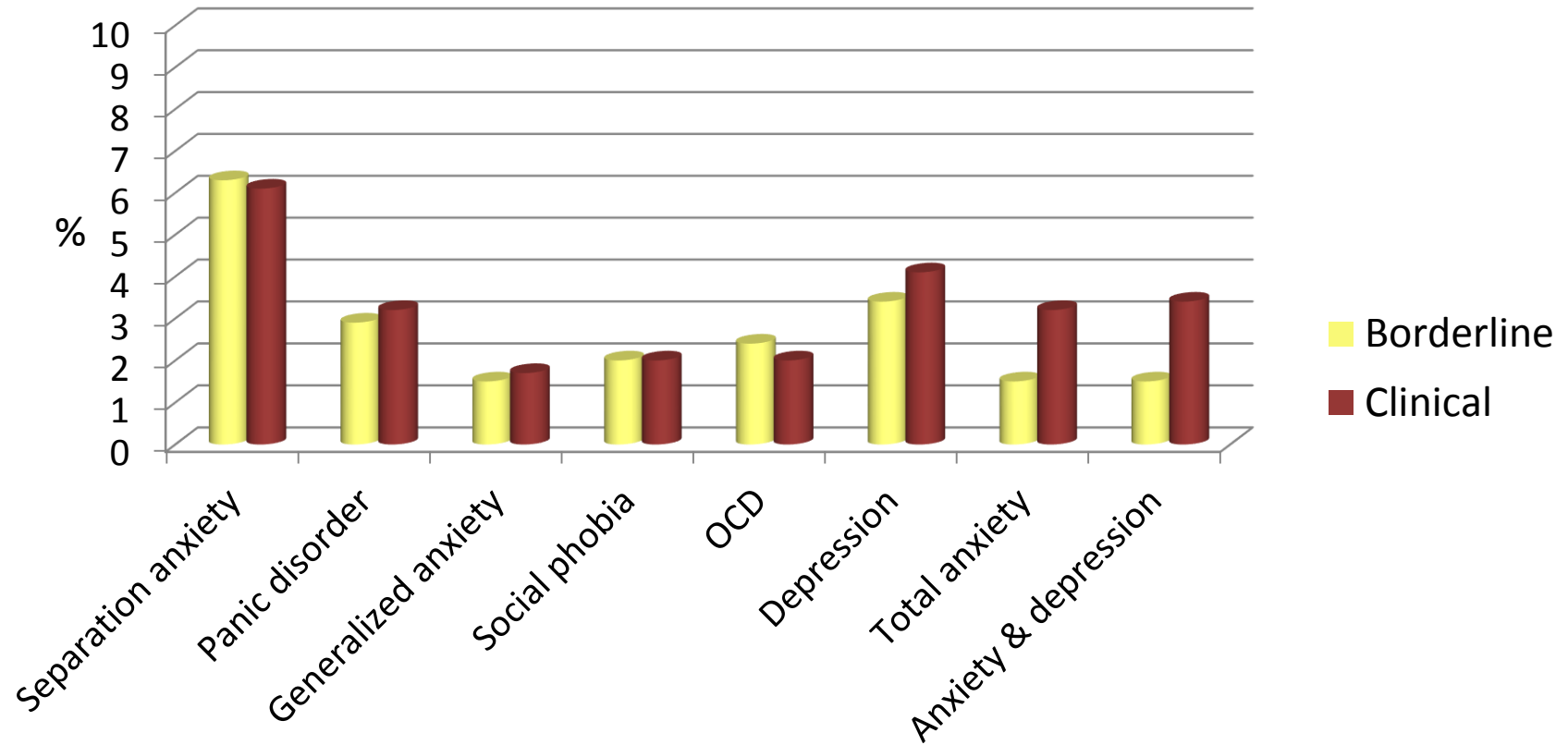Legend:
- 6 to 10
- 11 to 14
- 15 to 17
- 18 to 21

Primary Diagnosis

PedsQL-IM Scores

Percent

Data points:
- Angry: 21.5
- Afraid: 28.5
- Sad: 36.8
- Worried: 58
- Pain: 59.3
- Tired: 77.3

RCADS Scores

Reliability

Domain Sampling Theory

Internal consistency   coefficient alpha (stand. Items) = .71
Item-item correlations r = .319 to .495 with ≥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

PedsQL-IM items	Component	
	1	**2**
I feel afraid or scared	**.830**	-.012
I feel sad or blue	**.569**	.412
I feel angry	**.434**	.534
I worry about what will happen to me	**.756**	.133
I feel tired	.029	**.805**
I feel pain	.117	**.794**

Extraction Method: Principal Component Analysis
Rotation Method: Varimax with Kaiser Normalization
Rotation converged in 3 iterations

Component Plot in Rotated Space
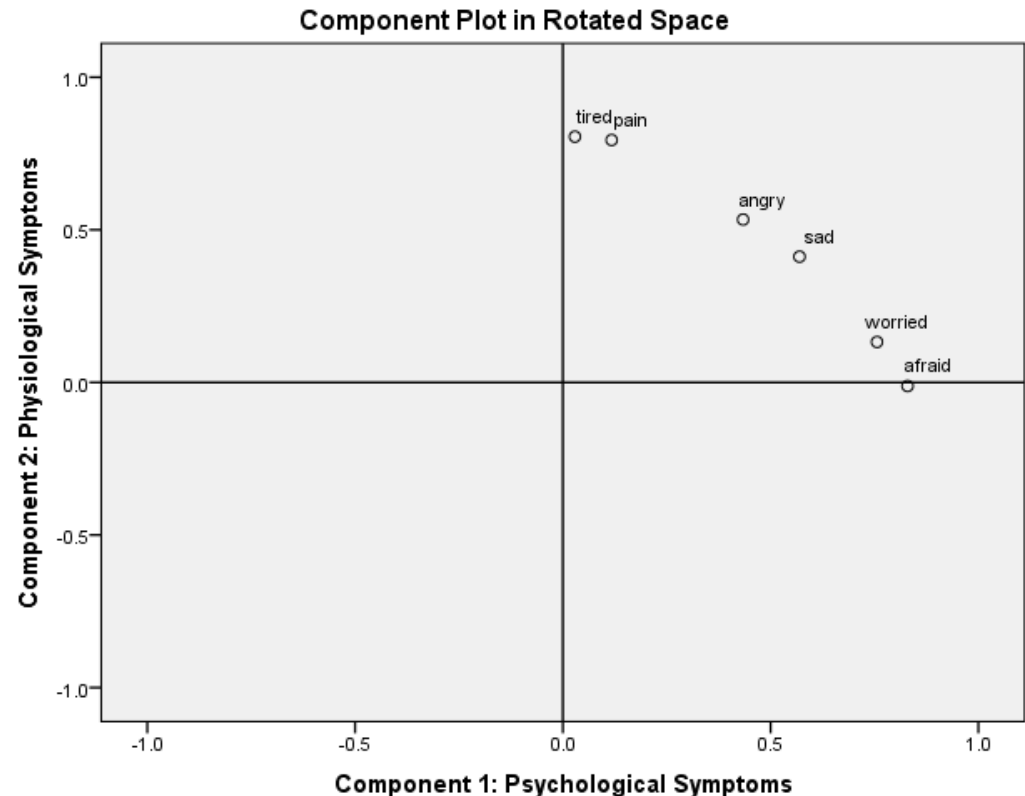
Correlations >.30 between PedsQL-IM items & RCADS scales (all $p <$ .001)

	Afraid	Sad	Angry	Worried	Tired	Pain	Total Score	Emot. Distress
Separation anxiety				.347			.366	.384
Generalized anxiety				.477			.405	.403
Panic disorder				.354			.390	.341
Social phobia				.357			.354	.332
OCD							.300	
Depression				.422	.405	.318	.528	.432
Total anxiety				.447		.356	.452	.428
Anxiety & depression	.301			.464	.315		.494	.452

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 .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