

Health Related Quality of Life in Children with Thoracic Insufficiency Syndrome

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and the Chest Wall and Spinal Deformity Study Group



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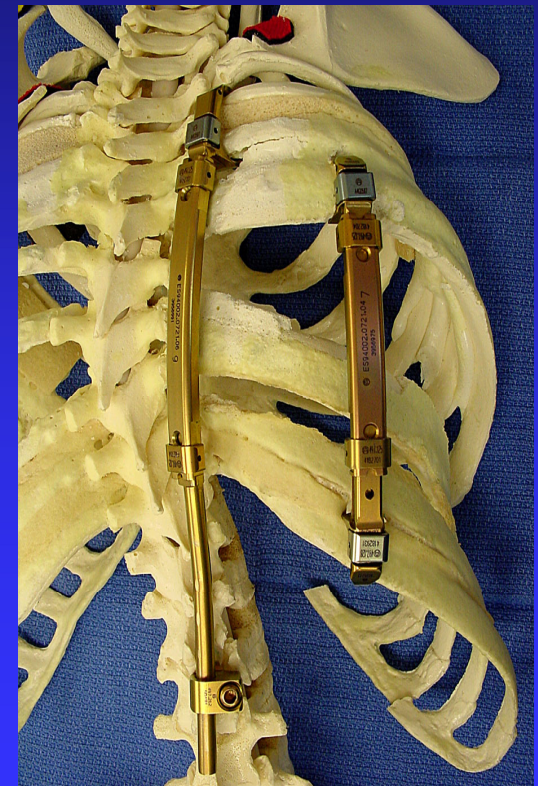
Columbia Orthopaedics
Pediatric Orthopaedic Surgery

Purpose

The purpose of this study was to examine the effect of early onset scoliosis on health related quality of life prior to implantation of the VEPTR

Methods

- Retrospective review of original multi-center database of the VEPTR - IDE
- Child Health Questionnaire Parent Form (CHQ) was collected on 45 patients treated with the VEPTR
 - Patients > 5 yo
 - Parent administered



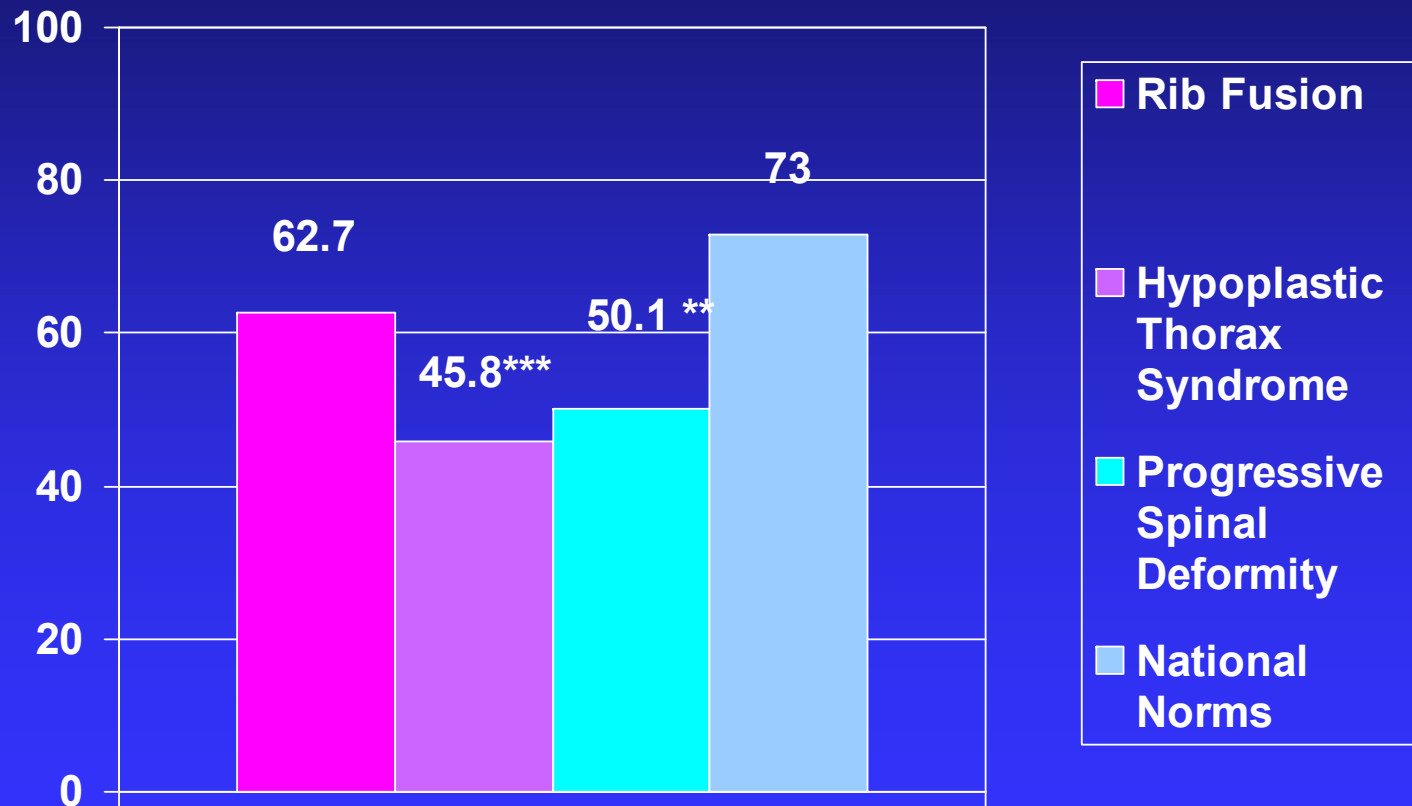
Child Health Questionnaire (CHQ)

- Landgraf and Ware '90. Released 1/97**
- Versions: PF 98/ PF 50/ PF 28/ CF 87**
- age-adjusted normative values available**
- extensively validated with scores for many diseases**

Methods

- **8.2±2.6 !! years (preop assessment)**
- **10.4±2.4 years (postop assessment)**
- **Patients were divided into 3 diagnostic categories:**
 - **Rib Fusion (RF, N=15)**
 - **Hypoplastic Thorax Syndrome (HT, N=17)**
 - **Progressive Spinal Deformity (PS, N=13)**

General Health

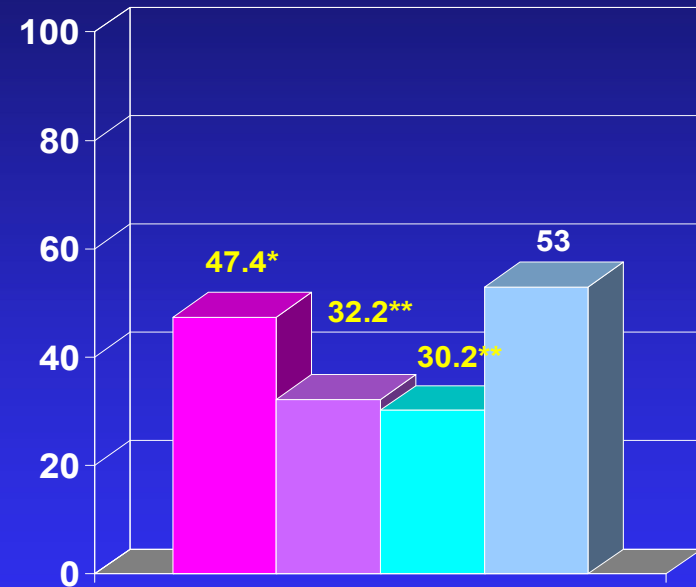
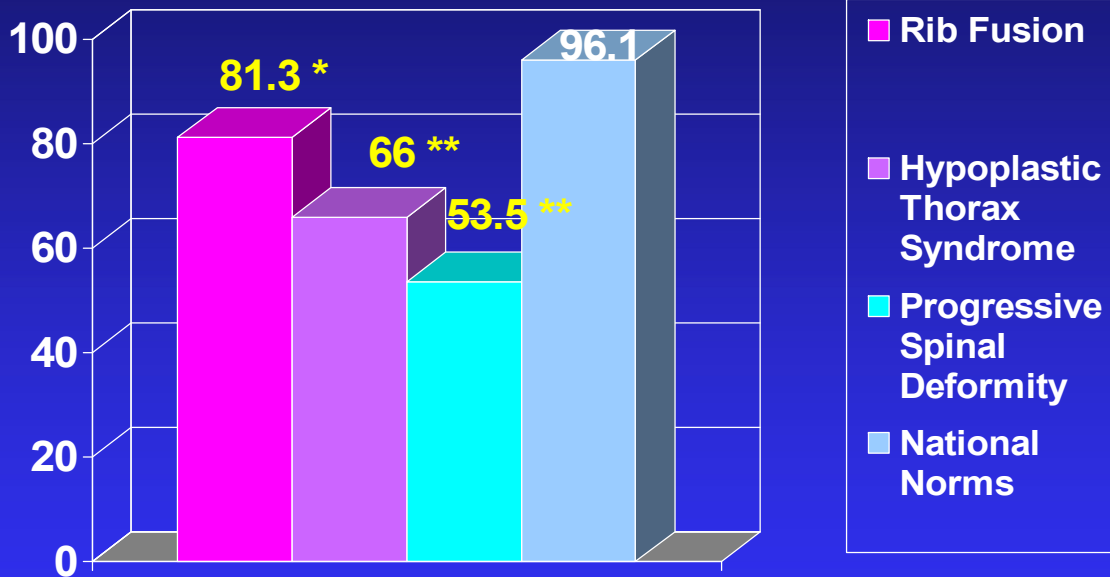


General Health of this Population Much Worse than Age Adj Norms

Results

Physical Functioning

Physical Summary



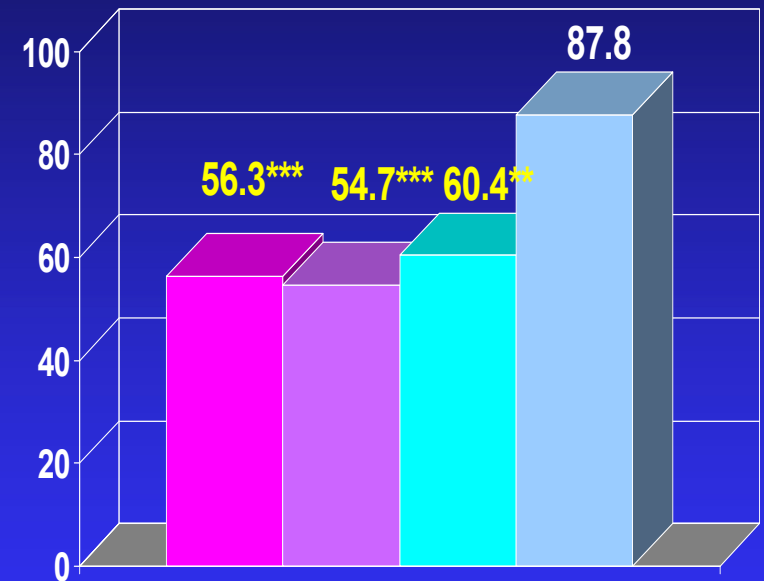
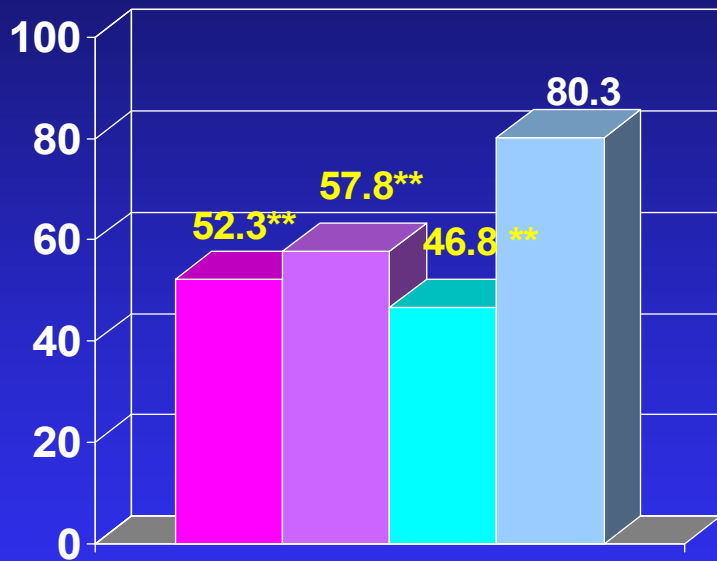
*p<.05 **p<.01 ***p<.001

**Significant limitations in physical domains
compared with healthy children**

Results

Parental Impact -Emotional

Parental Impact-Time



*p < .05 **p < .01 ***p < .001

Significant impact on parents compared with parents of healthy children

Conclusions: QOL in TIS

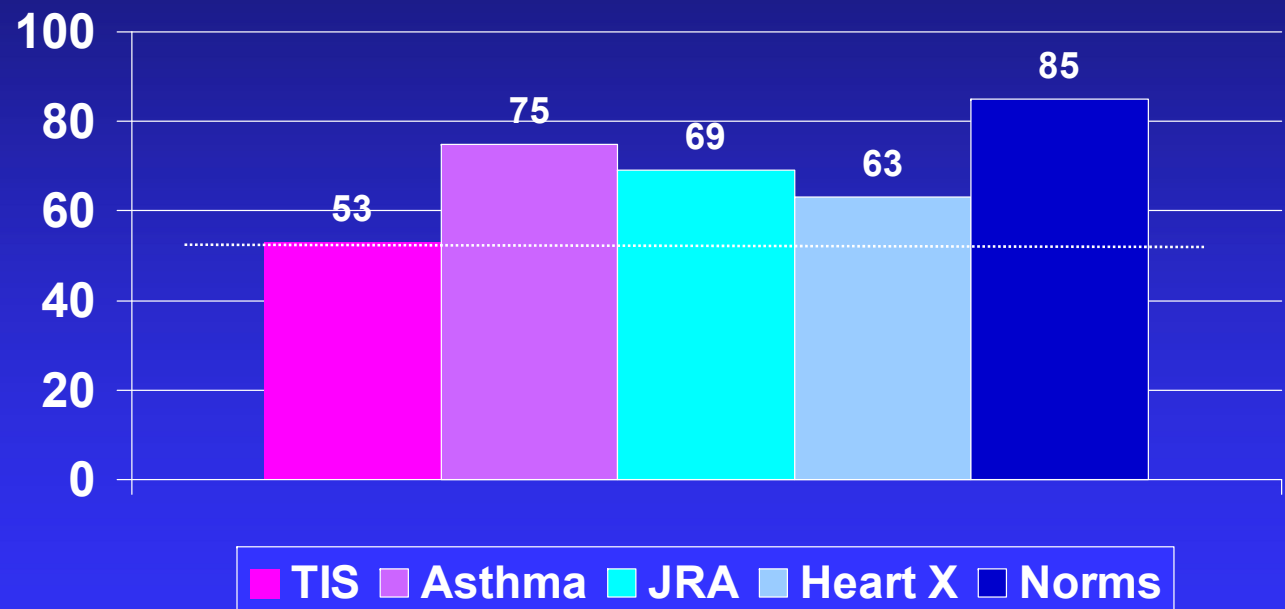
- These scores are among the lowest observed in pediatrics

- Asthma

- JRA

- Heart transplant

QOL in Pediatrics



Discussion

- Children with EOS have poor quality of life
 - Much different than AIS
- Is it driven by comorbidity, spine deformity or treatment ?

Further Research

- Develop better ways to measure quality of life in these children, esp < 5 yo
- Examine effect of VEPTR expansion pre and post VEPTR prospectively
- Current efforts are underway to compare these patients post VEPTR to similar group of growing rods / early fusion

Thank You



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