MICHIGAN STATE UNIVERSITY | College of Nursing

Quality of Life Perspectives in Children with Cerebral Palsy

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Introduction

- Focus is on results of 2 studies.
- Examining QoL perceptions among school-age children with cerebral palsy and their typically developing peers.
- Part of a larger study of social integration of children with disabilities.

Definition of Quality of Life

- WHO 1997 definition:
  - "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns."
- NIH PROMIS Steering Committee (2009) opted to retain the WHO QoL framework of physical, mental and social health.

Topics of Interest of the Two Studies

1. The feasibility of utilizing a modified self-generated child-reported quality of life instrument with children, from ages 6-12, with and without cerebral palsy.
2. To generate information about differing perspectives (child-reported vs. parent-proxy reports) and differing domains (predetermined vs. self-generated) on QoL of school-age children with and without cerebral palsy.

Hypotheses of Study One

1. Children, ages 6-12 years, will be able to self-generate QoL domains using a modified Schedule for the Evaluation of Individual Quality of Life-Direct Weight (SEIQoL-DW) procedure;
2. Group difference in SEIQoL-DW Total Index Score will not be statistically significant; and
3. Group differences in frequency, ranking and status of domains will not be statistically significant.

Method: Sample

- *n* = 101 school-age children, 6-12 years
- 41 children with cerebral palsy (CP)
- 60 typically developing (TD) children

Method: Sample

Inclusion/Exclusion Criteria for all children

- IQ 70 or greater
- Functional oral communication skills
- Public or Private schooling
- Absence of current psychiatric diagnosis
- Absence of any recent medication changes that could affect cognition

Method: Sample

Inclusion/Exclusion Criteria for children with CP

- Only a history of congenital CP with no history of post-neonatal acquired brain injury (i.e., traumatic brain injury, stroke, encephalitis, or injury secondary to status epilepticus)

Method: Sample

Inclusion/Exclusion Criteria for TD children

- No history of cognitive, functional, or physical impairments, no special education certification, and no diagnosis of CP.

Method: Sample

	Cerebral Palsy (CP) **(n = 41)**	***Typically Developing (TD)*** **(n = 60)**
Age (years)	**8.8 (1.8)**	**8.9 (1.7)**
Gender		
Male	**27**	**30**
Female	**14**	**30**
Seizure History	**27% positive****	**0% positive****
Birth weight (grams)	**2113.72 (1097.68)****	**3468.56 (513.0)**
Gestation (weeks)	**30.6 (6.4)****	**37.7 (1.1) ****

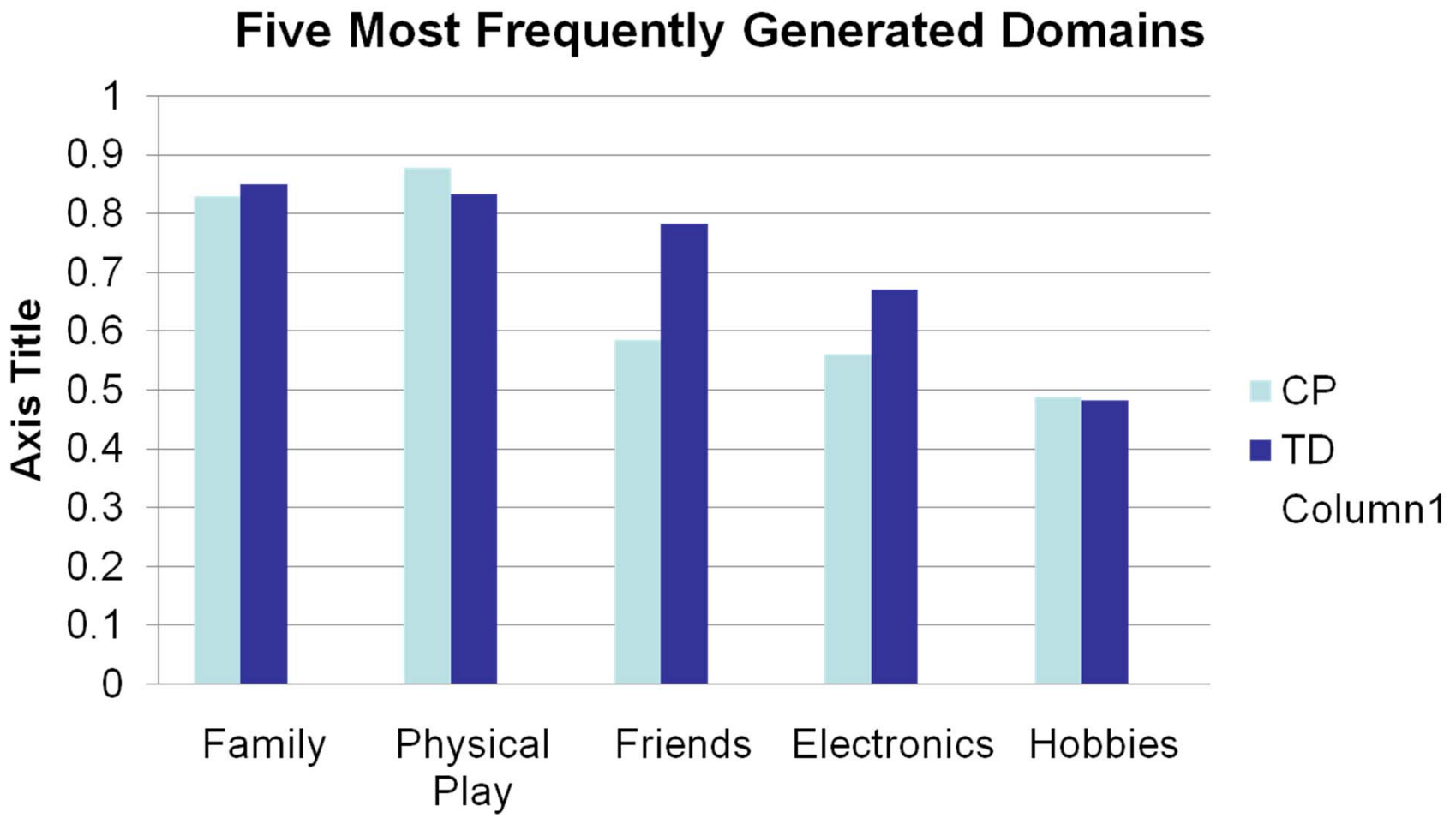
GMFCS levels as follows: Level 1 (5), Level II (1), Level III (17), Level IV (5), Level V (1) and 12 children classified as having no restrictions and no limitations.

Instrument: SEIQoL-DW modified

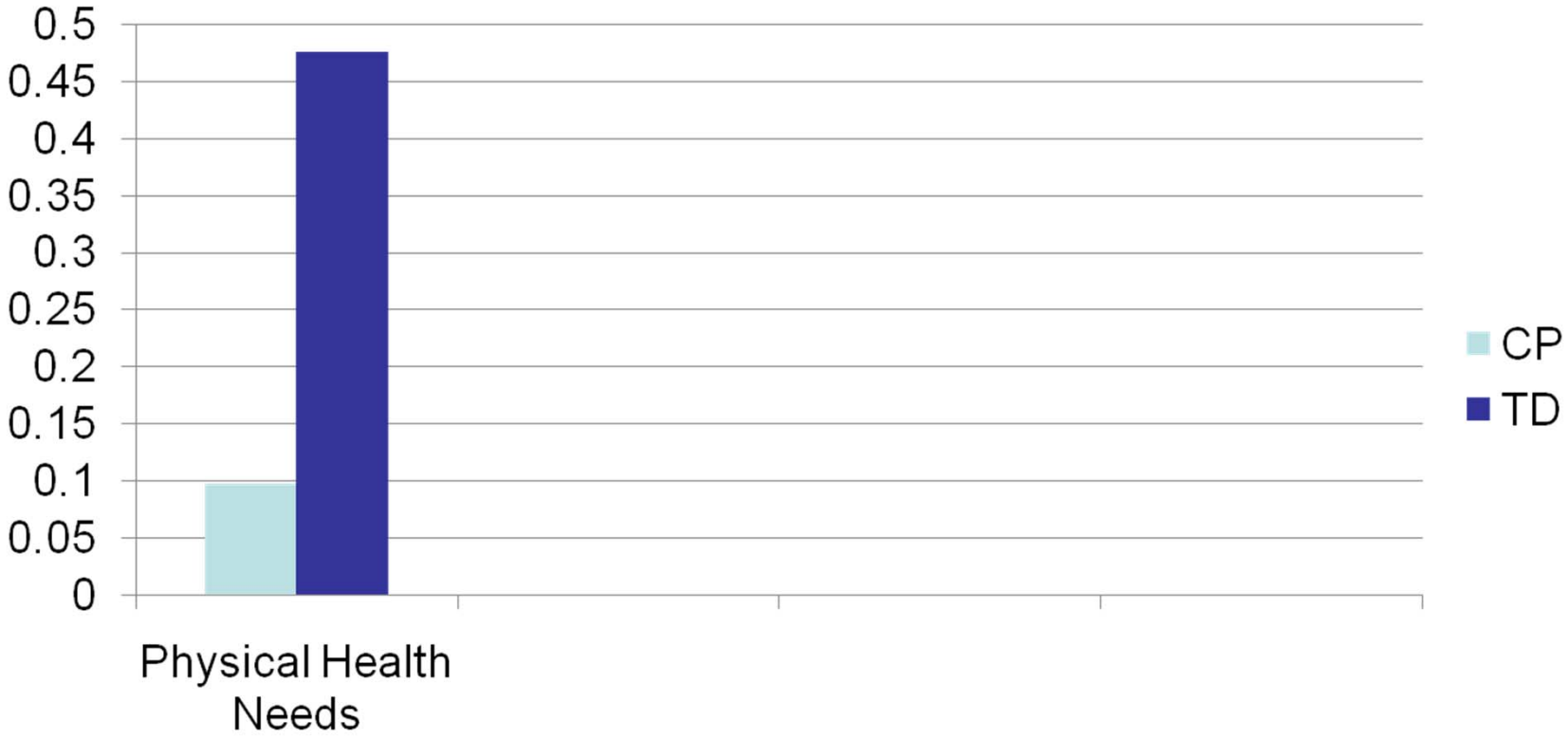
- Semi-structured interview QoL instrument by which individuals identify domains or importance.
- Three Stages
  - Stage 1 – nominate 5 domains of importance
  - Stage 2 – Rate the domains
  - Stage 3 – Rank the domains

Results of Study One

- 11 quality of life domains were self-identified:
  - Family
  - Friends
  - Pets
  - Hobbies
  - Physical Play
  - Physical Health/Physical Needs
  - School/Education
  - Religion
  - Electronics/Entertainment
  - Travel
  - Other


Five Most Frequently Generated Domains
Axis Title
1
0.9
0.8
0.7
0.6
0.5
0.4
0.3
0.2
0.1
0
Family
Physical Play
Friends
Electronics
Hobbies
CP
TD
Column1

Statistically Significant Difference in SEIQoL Frequency Domains For Physical Health/Physical Needs Domain



- Group difference in SEIQoL-DW Total Index was not significantly different and there were no statistically significant group differences in satisfaction ratings
- There were no statistically significant associations between GMFCS and the SEIQoL-DW in the CP group

Study Two "Differing Perspectives" Questions

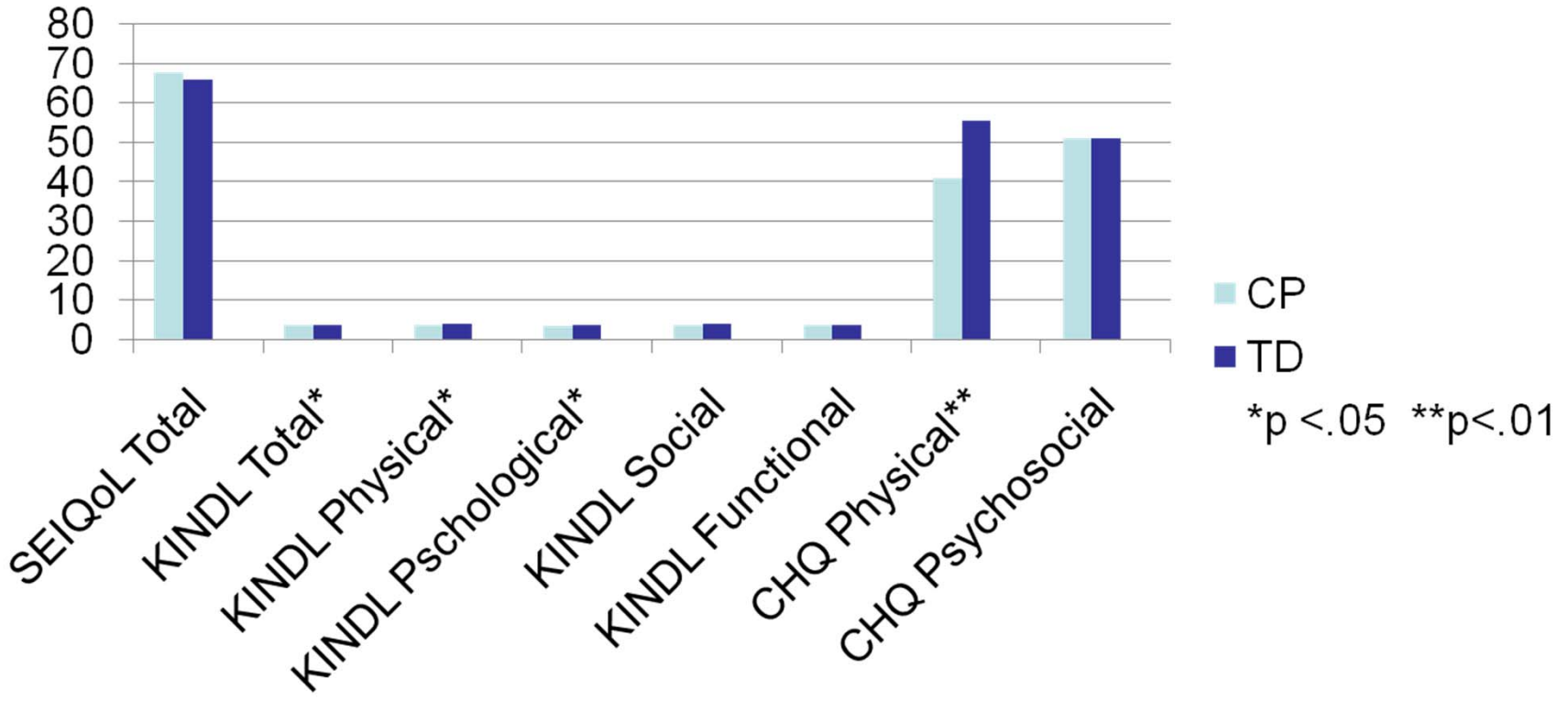
1. What are the associations between predetermined and self-generated QoL domains in school-age children with CP and their typically developing (TD) peers?
2. What is the concordance between child-rated QoL and parent ratings of the child's HRQoL in children with and without CP?

Study Two: Instruments & Method

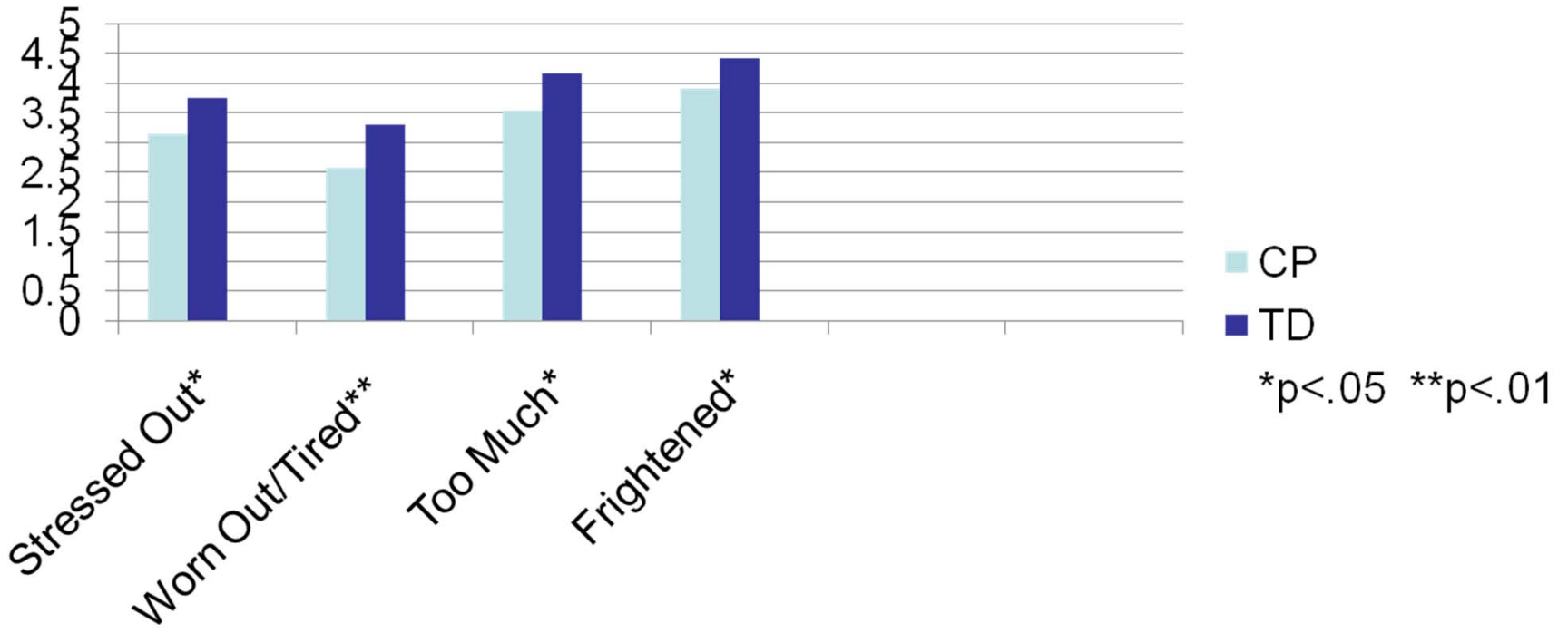
- Kinder Lebensqualititafragebogen (KINDL) (Ravens-Sieberer & Bullinger, 1998),
- Child Health Questionnaire (CHQ) (Landgraf, Abetz, & Ware, 1996), and
- SEIQoL-DW modified.

RESULTS

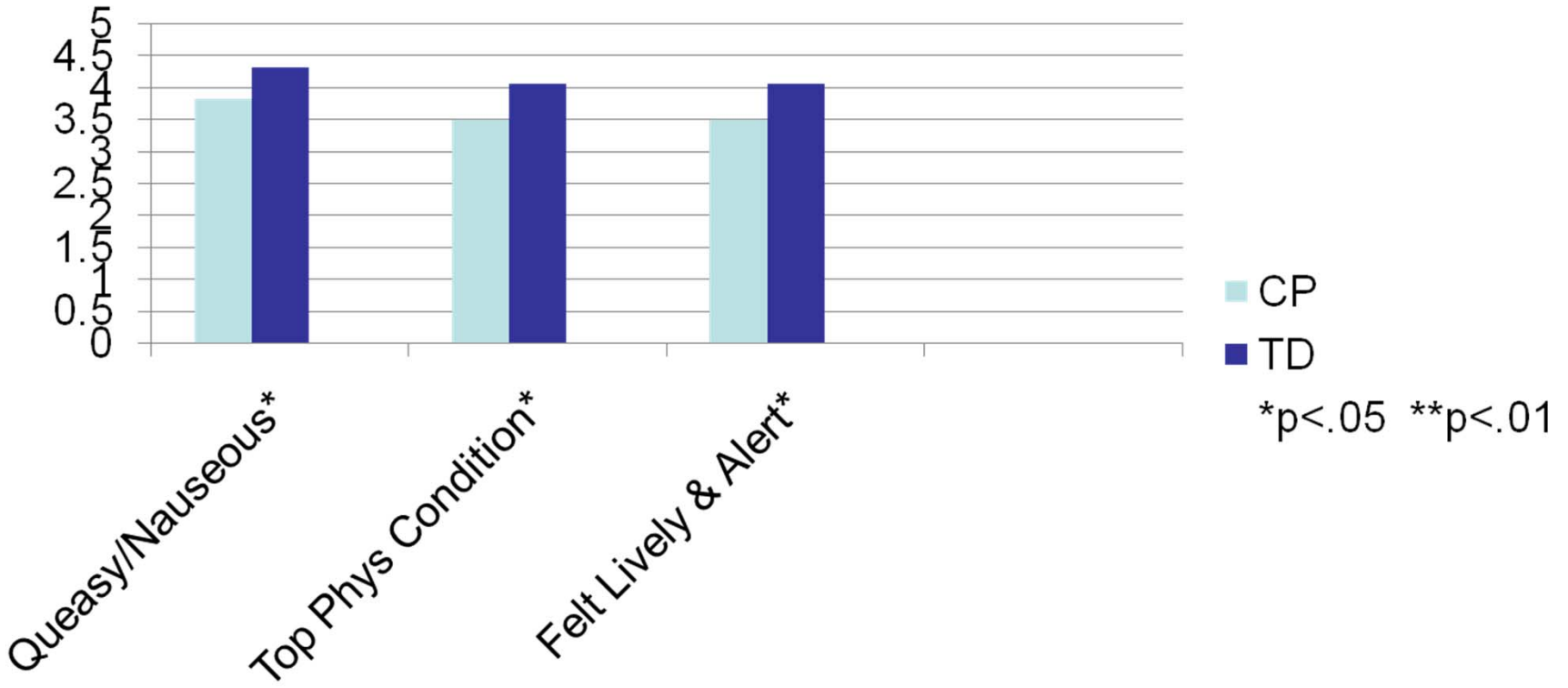
Means & SD for SEIQoL, KINDL, CHQ



Statistically Significant Means & SD for KINDL Psychological Scale – Individual Items

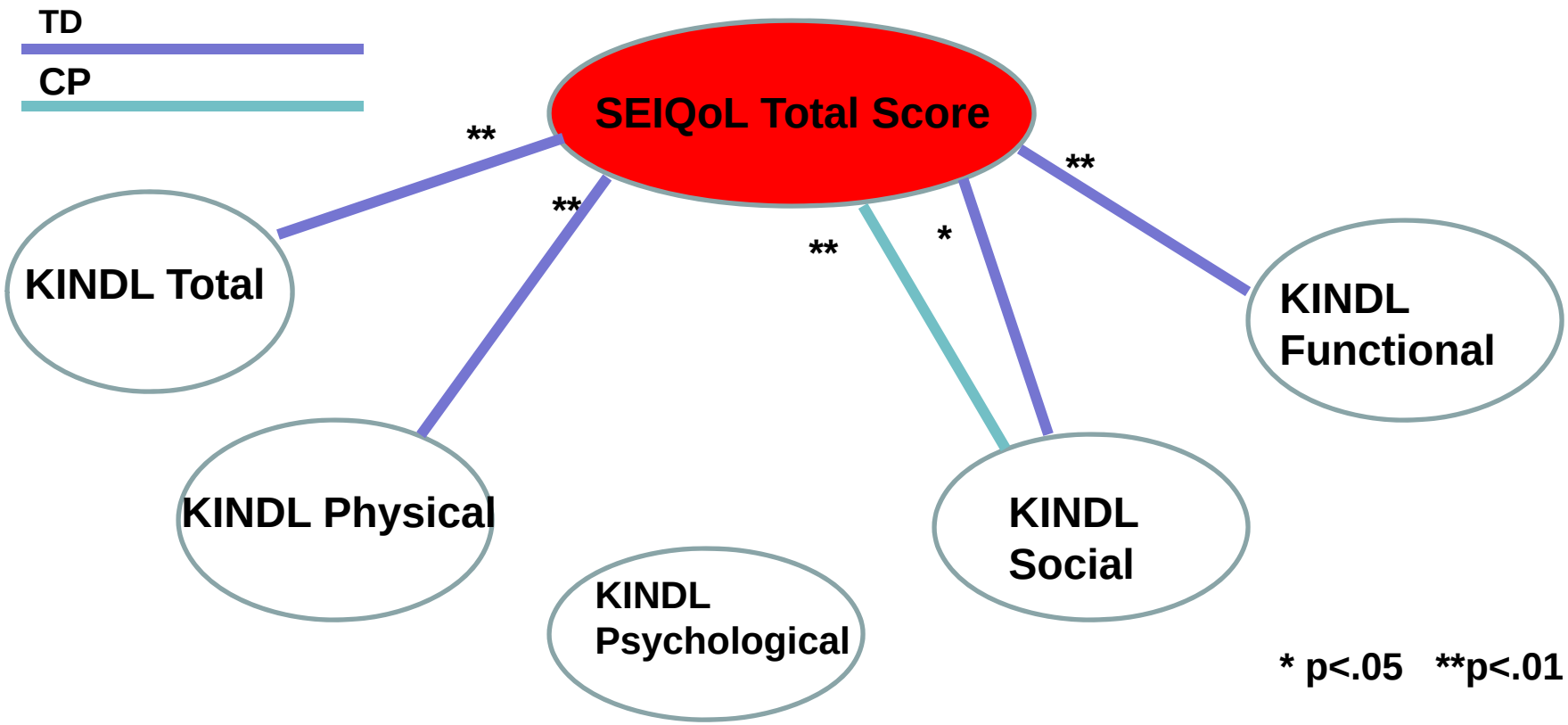


Statistically Significant Means & SD for KINDL Physical Scale – Individual Items



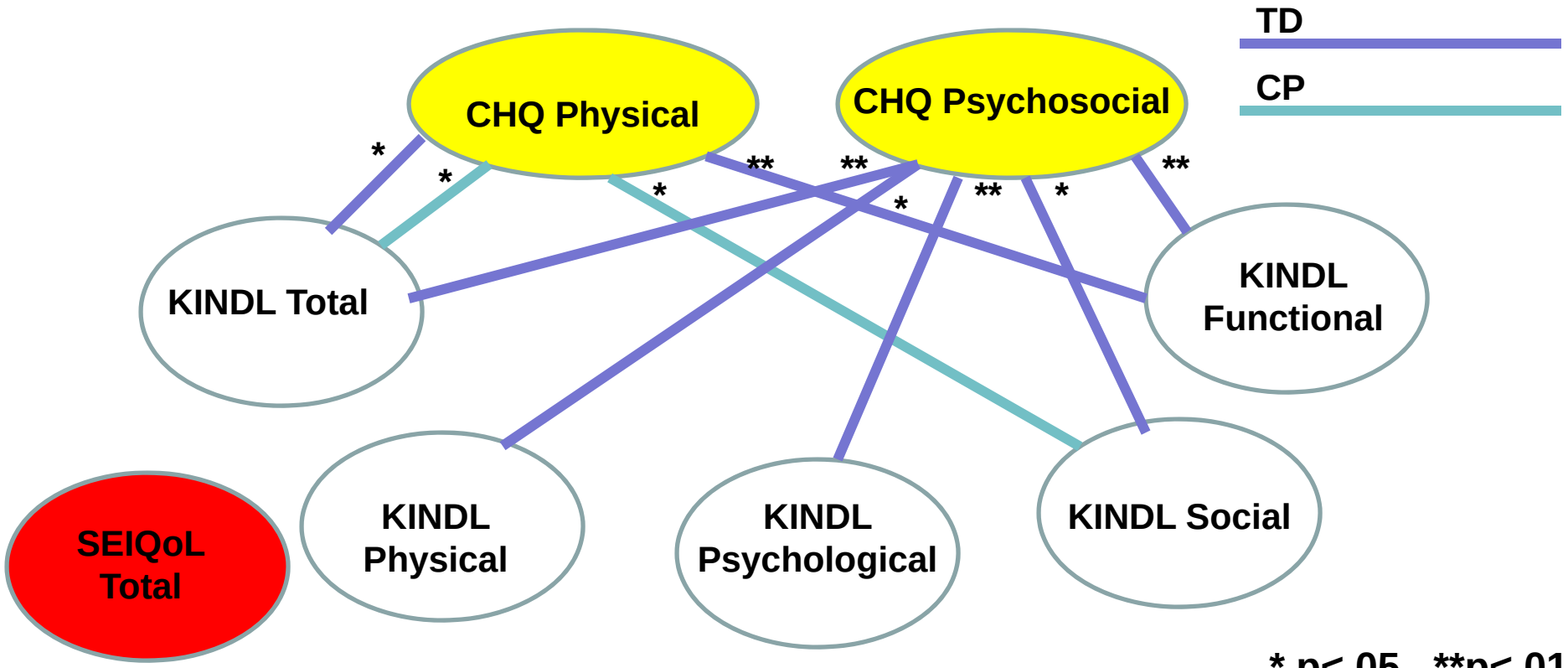
Pearson Bivariate Correlations

Child Self-generated, Self-reports with Child Predetermined, Self-reports



Pearson Bivariate Correlations

Parent-Proxy Predetermined with Child, Predetermined and Child, Self-generated



- Which raises the interesting possibility that parents of children with cerebral palsy may not be aware of the extent to which these children experience non-observable feelings of stress.

- And, it leads to the possibility that these psychological symptoms may be erroneously identified as symptoms ascribed to the condition of cerebral palsy which may be termed “neurodevelopmental diagnostic over-shadowing” or an example of “hidden morbidity” as described by Varni, Burwinkel and others in 2005.

Conclusion

- Children, ages 6-12 years, can self-generate dimensions of importance to their quality of life based on experience and developmental stage.
- Children with the unique health condition of cerebral palsy self-generate a list physical and social dimensions of importance that are not radical differences from their typically developing peers.

Conclusion

- Both children and parent perspectives and expectations should be assessed as complementary views rather than opposing or confirmatory views.

Conclusion

- Broader assessment of children with cerebral palsy may need to be considered beyond the motor and physical functional abilities to include the less obvious psychological and emotional comorbidities that impact a child's quality of life.