What Is the Level of Agreement between Family Caregivers and Their Children Living with Rheumatic Disease in Reporting Health-Related Quality of Life?

Department of Population Health Sciences
Duke University School of Medicine

Ya-Ning Chan, PhD, RN[1]; Kaveh Ardalan, MD, MS[2]; Li Lin, MS[1]; Dandan Chen, PhD[3]; Laura E. Schanberg, MD[2, 4]; Richard K. Vehe, MD[5]; Bryce B. Reeve, PhD[1,4]; for the CARRA Registry Investigators

[1]Department of Population Health Sciences, Duke University; [2]Department of Pediatrics, Division of Pediatric Rheumatology, Duke University; [3]Department of Surgery, Massachusetts General Hospital; [4]Duke Clinical Research Institute; [5]Department of Pediatrics, Division of Pediatric Rheumatology, University of Minnesota

BACKGROUND

- Children with juvenile idiopathic arthritis (JIA) and systemic lupus erythematosus (SLE) experience lower health-related quality of life (HRQOL) than healthy general pediatric population.
- Child self-report is considered the gold standard for understanding their HRQOL; however, when obtaining child self-report is not feasible, caregiver-report is needed.
- Limited studies on the relationship between child self-report and caregiver-report on HRQOL measures; mixed findings were identified in associated factors.

Objectives

- Determine agreement between child self-report and caregiver-report HRQOL in JIA and SLE.
- Identify factors (demographic and clinical) associated with the level of agreement.

METHODS

- Data source: The Pediatric Patient Reported Outcomes in Chronic Diseases (PEPR) study using CARRA Registry
- Time points of assessment: Baseline, 6 months, and 12 months
- Measures: The NIH Patient-Reported Outcomes Measurement Information System® (PROMIS®) Pediatric Self-Report and Parent-Proxy Measures
- Statistical methods:
  o Level of agreement: One-way random-effects model for intraclass correlation coefficient (ICC) estimation
  o Associated factors: Multivariable mixed-effect models
   ▪ (Child self-report measure score) – (Parent-proxy measure score)

RESULTS

Sample Characteristics (451 child-caregiver dyads)

- Child mean age 13.8 years, 87.1% JIA, 71.4% female, 74.3% White, 90.5% non-Hispanic
- Caregiver 55% with a high school degree or above, 29.4% with an annual household income >100k

Levels of agreement across HRQOL domains over time

- ICC remains stable over time across HRQOL domains.
- Strong agreement (ICC=0.50—0.68): mobility, physical activity, fatigue, and pain interference.
- Mild agreement (ICC=0.34—0.42): family relationship and anxiety.
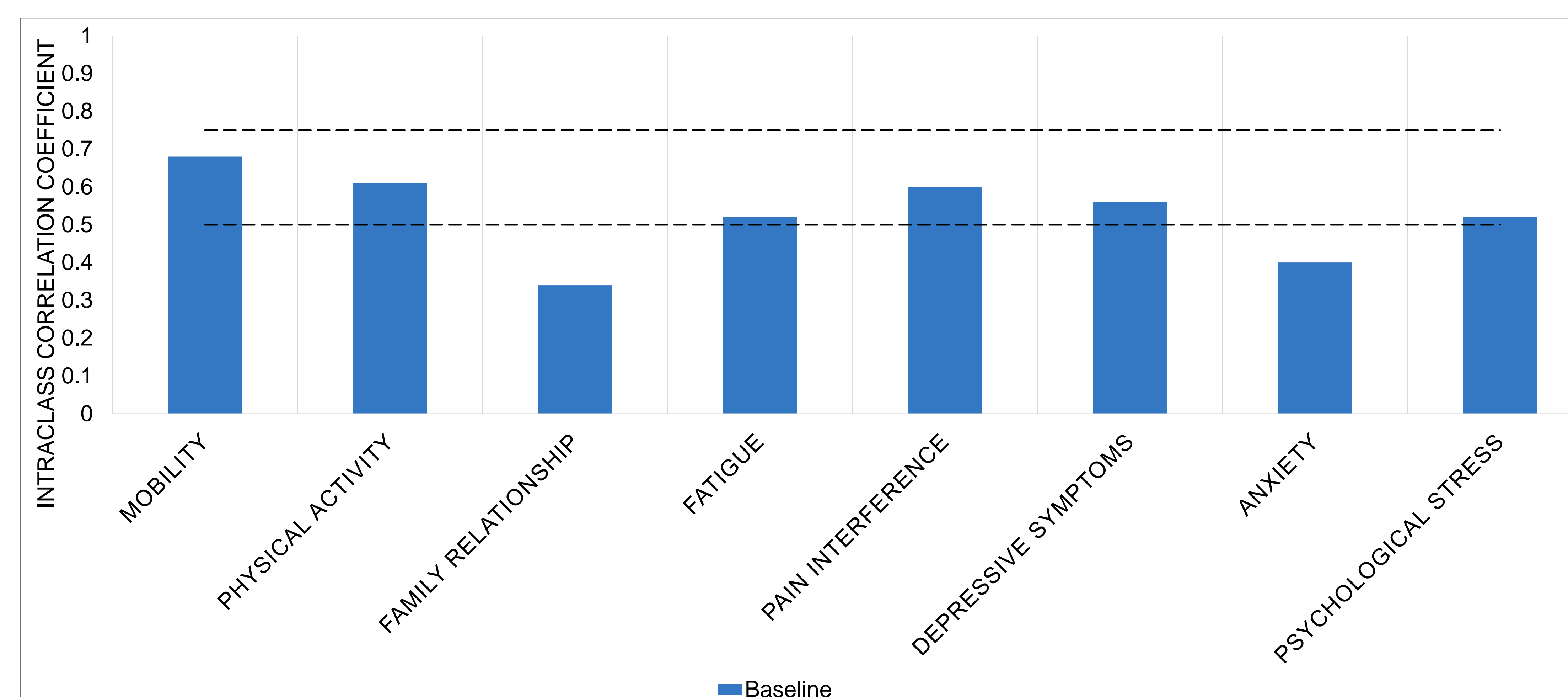
Factors associated with levels of agreement across HRQOL domains

Caregivers tended to give lower scores for their children's functioning and higher scores for their children's symptom burden.

- Older (vs. younger) child: better agreement on mobility, fatigue, pain interference, anxiety, psychological distress, and depressive symptoms.
- Female (vs. male) child: better agreement on psychological distress and depressive symptoms.
- No significant findings on disease types (SLE vs. JIA), disease duration, and body mass index.

LIMITATIONS

- Limited caregiver information and homogeneous sample (non-Hispanic, White, English speaking)
- All HRQOL domains were not assessed at all three time points.
  o Physical activity: baseline & 6 months
  o Family relationship: baseline & 12 months
  o Psychological stress: baseline

CONCLUSIONS

- Levels of agreement are stable over time but vary based on HRQOL domains.
- Caregivers can provide complementary information on physical aspects of HRQOL but child self-report remains as the ultimate source.

CONTACT

Ya-Ning Chan, PhD, RN   ya-ning.chan@duke.edu