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Use of the Patient Reported Outcomes Measurement Information System (PROMIS) in a Pediatric Cohort with Inflammatory Bowel Disease (IBD)

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Background: PROMIS provides valid self-reported measures of physical, emotional, and social health that can inform research and clinical care in children with chronic conditions. To date, PROMIS tools have not been evaluated in children with IBD.

Objective: To evaluate PROMIS tools relative to disease activity and IBD-specific quality of life measures in a pediatric IBD cohort.

Design/Methods: The Crohn's and Colitis Foundation of America (CCFA) Partners Kids & Teens study is an internet-based cohort of children with IBD. We recruited children with Crohn's Disease (CD), Ulcerative or Indeterminate Colitis (UC/IC) via the CCFA. Participants age 9 to 17 self-reported symptoms, disease-specific health related quality of life (HRQOL) and PROMIS measures of pain interference, anxiety, depression, fatigue and peer relationships. We used descriptive statistics and bivariate comparisons to assess the relationships between PROMIS domains, disease activity [Pediatric Ulcerative Colitis Index (PUCAI) and Short Crohn's Disease Activity Index (SCDAI)], and the IMPACT-35 HRQOL instrument.

Results: A total of 359 children, with self-reported IBD joined the CCFA Partners Kids & Teens study through October 2013. Of these, 158 (44%) were female; 273 (76%) reported CD, and 86 (24%) UC/IC. Increasing disease activity (per SCDAI and PUCAI), were associated with large and significantly worsening differences across all PROMIS domains ($p < 0.001$, Figure 1 below) with the exception of peer relationships amongst UC/ IC patients ($p = 0.06$). Similarly, better HRQOL ratings were associated with better function in all PROMIS domains ($p < 0.001$ for all). Disease remission was associated with significantly better function in all domains.

Conclusions: In a pediatric IBD population, PROMIS measures differentiate known clinical groups with expected direction and magnitude of differences. PROMIS is a potentially powerful tool for outcomes

Figure 1:

