Concordance Levels in Pediatric and Parent Proxy Responses Minha Ghani,¹ Abel Sandoval Gonzalez,² Tapasvini Paralkar,² S. Hadi Ahmed,³ Sawayer Stubbs,⁴ and Nico Osier^{4, 5}

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Purpose: To evaluate the concordance between parent-proxy and pediatric responses to self-reported health measures, following a traumatic brain injury (TBI), using data from a longitudinal study.

Background:

TBIs can result in short term or long term deficits in physical and psychological health (1).



It is important to systematically track symptoms, after a TBI, to elucidate possible patterns in the recovery process.



Clinical study's often rely on self-reported measures. Proxy responses are common when cognitive or physical deficits can effect a participants ability to self-report, as seen in this study due to age and/or injury.

Methods:

IRB approval was gained from the University of Texas at Austin and site approval was gained from Dell Children's Medical Center

This study enrolled participants aged 5 - 16 with TBIs (cases) or orthopedic injuries (controls). Responses were recorded for 5 Patient-Reported Outcomes Measurement Information System (PROMIS) measures at baseline, 3 and 6 months. Each of the 5 measures were completed by both the Pediatric participants and their parent-proxies. Responses from 90 participants were analyzed.

Data was pre-processed and analyzed using Microsoft Excel, python, Health Measures scoring service, and R programming language. Missing values were imputed using the K-nearest neighbors method.

Measures of Concordance:

- Cosine Similarity was calculated by measuring the angle between the trajectory (i.e change over time) of participants' T-scores for a survey compared to those reported by their parent-proxy.
- Normalized Average Difference was calculated by finding the average of the difference between pediatric and parent-proxy Tscores reported at each time period and normalizing it by the standard deviation of the PROMIS reference population.

Results:

No significant differences were found between:

- pediatric vs. parent-proxy survey responses
- participants of differing ages, ethnicities, sexes, or injury type
- type of survey, positive or negative, or specific survey

Limitations:

missing data points, limited scales, and small sample size

Future Studies:

- replicating finding in a larger, more racially diverse population
- exploring effect of proxy relationship and sex on concordance



Figure 2. Variability in responses affected by Demographic Factor alpha level = 0.05









Figure 1. Average cosine similarities for the PROMIS surveys