THE DEVELOPMENT AND READABILITY OF THE CONCUSSION QUALITY OF LIFE SCALE-YOUTH FOR ASSESSING HEALTH-RELATED QUALITY OF LIFE FOLLOWING SPORT-RELATED CONCUSSION

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Background: While the assessment of symptoms, cognition, balance, and oculomotor function is common among sports medicine clinicians, there has been increased attention on assessing the patient's perception of their health status following concussion. Recent recommendations suggest the use of patient-report outcome instruments (PROs) as part of the concussion evaluation to assess health-related quality of life (HRQOL) to aid in managing the injury. At present, there is not a concussion-specific PRO developed for the assessment of HRQOL in the pediatric population. Therefore, our purpose was to develop and assess the readability of a concussion-specific HRQOL measure, the Concussion Quality of Life Scale-Youth (CQOL-Y), using a mixed method approach.

Methods: For instrument development and initial item generation, we analyzed prospectively collected data from three prior studies of HRQOL that used the Pediatric Quality of Life Inventory, Multidimensional Fatigue Scale, Headache Impact Test, and Patient-Reported Outcomes Measurement Information System outcome scales. Additionally, categories and themes from a prospective qualitative study of HRQOL following concussion were analyzed. Item themes were included in the initial item generation if the item was endorsed by greater than 15% of participants at day 3 or day 10 post-injury. As part of the gap analysis, a review of the literature was also conducted for studies of HRQOL following concussion to determine domains affected after injury and to review individual items on the PROs utilized in those studies. For readability assessment, we used two approaches: participant-based and computer-based assessments. For participant-based assessment of readability sixteen participants (7 children; 10.3±1.4 years, 5.4±1.5 grade level; 9 adolescents 14.2±1.7 years, 9.4±1.6 grade level) were recruited. The San Diego Quick Assessment of Reading Ability was used to determine each participant's reading grade level. Participants then read each item of the CQOL-Y and circled words that they did not understand. Frequency counts were determined for each word identified by participants, for each item, domain, and the total CQOL-Y. For computer-based assessment of readability, the Flesch Reading Ease (FRE) and Flesch-Kincaid Reading Level (FK) scores were calculated for each item, domain, and the total CQOL-Y. The FRE is scored 0-100, with lower scores indicating more difficult reading material. The FRE score is converted to the FK, an approximate reading level, ranging from pre-primer (<0) to college (>12), with higher reading level indicating more difficult reading material. Summary statistics were used to report scores for each item, domain, and the total CQOL-Y. Independent t-tests were used to determine whether differences existed between children (7-12 years) and adolescents (13-18 years) on the San Diego Quick Assessment of Reading Ability and the word difficulty endorsement.

Results: For instrument development, after eliminating items that were endorsed by fewer than 15% of patients, we had a total of 27 items from the established PROs related to school and cognition, social, sleep and fatigue, activities of daily living, and sport participation that were reworded to be more specific to the athletic population. The gap analysis also identified a lack of emotion or mood related items. The initial item generation phase resulted in 50 HRQOL items and 3 single-item questions in the following domains identified as important to adolescents following concussion: cognitive and school (12 items), social (11 items), mood and emotions (13 items), sleep (8 items), and activities of daily living and sport participation (6 items). For participant-based assessment of readability, the average reading levels of the participants was 6.14±1.07 (range 5-

8) in children and 8.78±1.40 (range 6-10) in adolescents, which was significantly different between groups (p=.001). For the total CQOL-Y scale, children identified difficulty with .44±.73 words (range 0-4) and adolescents identified 0.33±0.71 (range 0-2 words), which was not different between groups (p=.263). Among children, difficulty was noted with irritable, errands, isolated, and occurred, whereas adolescents identified irritable and cognitive. The computer-based readability analysis of the FRE for items ranged from 34.5 to 100. The FRE of the scale as a whole was 67.6 with domains ranging from 75.4-95.3. The FK reading level ranged from 0 to 9.8 across items with a total FK score of 5.6 and domain scores ranging from 2.2-5.6.

Conclusion and Significance: Using a mixed methods approach to scale development, including context identification, concept elicitation, and item pool development, we have identified a 50-item scale to assess HRQOL following concussion. The initial analysis of readability suggests the overall scale was written at an appropriate reading level for children and adolescents. Future steps of scale development, including an expert panel review, item response theory model selection, item reduction, and field-testing will be conducted to improve readability of individual items and the patient acceptability of the CQOL-Y.

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