Concordance of Child and Parent Reports of Health-Related Quality of Life in Children With Mild Traumatic Brain or Non-Brain Injuries and in Uninjured Children: Longitudinal Evaluation

Pam Pieper, PhD, ARNP, PPCNP-BC, & Cynthia Garvan, PhD

ABSTRACT

Introduction: This study aimed to determine (a) concordance between parents' and children's perceptions of health-related quality of life (HRQoL) for children who sustained a mild traumatic brain injury or a mild non–brain injury or who were uninjured at baseline and at 1, 3, 6, and 12 months postinjury; (b) test-retest reliability of the Pediatric Quality of Life Inventory Generic Core and Cognitive Functioning Scales in the uninjured group; and (c) which, if any, variables predicted parity in child/parent dyad responses.

Methods: This longitudinal study included 103 child/parent dyads in three groups. Each child and parent completed Pediatric Quality of Life Inventory questionnaires within 24 hours of injury and at months 1, 3, 6, and 12 postinjury.

Results: Child/parent HRQoL concordance was generally poor. The variables for age, gender, and study group were not found to be response-parity predictors.

Discussion: Inclusion of child and parent perceptions provides a more comprehensive picture of the child's HRQoL, increasing provider awareness of related health care needs. J Pediatr Health Care. (2015) *29*, 343-351.

KEY WORDS

Agreement, concordance, health-related quality of life, longitudinal, mild traumatic brain injury, PedsQL

Pam Pieper, Clinical Associate Professor, University of Florida College of Nursing, and Nurse Practitioner, Division of Pediatric Surgery, University of Florida College of Medicine, Jacksonville, FL.

Cynthia Garvan, Biostatistician and Research Associate Professor, University of Florida College of Nursing, Jacksonville, FL.

This research was supported by grants from the American Pediatric Surgical Nurses Association and the Florida Nurses Association.

Conflicts of interest: None to report.

Correspondence: Pam Pieper, PhD, ARNP, PPCNP-BC, University of Florida College of Nursing, 653 W 8th St, L-4, Jacksonville, FL 32209; e-mail: pam.pieper@jax.ufl.edu.

0891-5245/$36.00

Published online March 4, 2015.

http://dx.doi.org/10.1016/j.pedhc.2015.01.008

Concordance between child and parent perceptions of a child's health-related quality of life (HRQoL) has

been studied in a number of populations from healthy children (Cremeens, Eiser, & Blades, 2006; Davis et al., 2007; Rebok et al., 2001; Theunissen et al., 1998) to children with chronic health conditions such as cancer (Parsons, Fairclough, Wang, & Hinds, 2012; Varni et al., 1998), brain or spinal tumors (Glaser, Davies, Walker, & Brazier, 1997), asthma (Ungar, Mirabelli, Cousins, & Boydell, 2006), spinal cord injuries (Oladeji et al., 2007), serious injuries in general (Gabbe et al., 2010), congenital hand differences (Ardon et al., 2012), and dental diseases (Jokovic, Locker, & Guyatt, 2004); however, no published literature was found in populations of children who have sustained mild traumatic brain injuries (mTBIs) or non-brain injuries (NBIs). The Centers for Disease Control and Prevention currently estimate annual TBI-related emergency department visits, hospital admissions, and deaths in the United States to be greater than 500,000 in children aged 0 to 14 years (Faul, Xu, Wald, & Coronado, 2010), making TBI an issue of major concern.

Eiser and Morse (2001), Upton, Lawford, and Eiser (2008), and Eiser and Varni (2013) have conducted systematic reviews on child/parent concordance regarding the child's HRQoL. In the latest publication, Eiser and Varni (2013) note that three generally accepted (but not universally observed) results have emerged from studies comparing child and parent perceptions of the child's HRQoL: (a) parents of healthy children tend to rate their children's HRQoL more highly than do the children themselves, whereas the opposite is true when children have a chronic health condition; (b) concordance is better in areas of observable functioning, such as physical domains, than those that are not observable, such as emotional and social domains; and (c) parent's personal HRQoL affects how they rate their child's HRQoL.

The aims of this study were to determine: (a) concordance between parents' and children's perceptions of HRQoL for children who sustained an mTBI or concussion or a mild NBI or who were uninjured (UI) at baseline and at 1, 3, 6, and 12 months postinjury; (b) test-retest reliability of the Pediatric Quality of Life Inventory (PedsQL) Generic Core Scales Total Scale Score and Physical and Psychosocial Health Summary Scores and the PedsQL Cognitive Functioning Scale in the UI group; and (c) which, if any, variables evaluated predicted parity in child/parent dyad responses.

METHODS

Sample

Initial participants included 120 child/parent dyads. (For purposes of this article, please note that *parent* refers to the child's parent, legal guardian, or primary caregiver who participated in the study). There were 40 dyads of 5- to 17-year-old children in each of three groups: those with an mTBI, those with mild NBIs, or UI children who were age- and gender-matched to those in the mTBI group. Children eligible for the mTBI group met requirements recommended by the World Health Organization Collaborating Centre Task Force on Mild Traumatic Brain Injury (Box; Carroll, Cassidy, Holm, Kraus, & Coronado, 2004). In addition, children in the mTBI group could have no significant associated NBIs and be hospitalized for no more than 24 hours. Children in the NBI group sustained nonoperative injuries such as closed fractures, dislocations, sprains, burns, lacerations, or bruises.

The initial plan was to age- and gender-match UI children with children sustaining mTBI (i.e., *friend sampling*; Gagnon, Swaine, Friedman, & Forget, 2005) to help control for potential confounding variables such as socioeconomic factors. For a number of reasons, this goal was not accomplished. Age- and gender-matched UI participants were therefore recruited from among people known to the principal investigator.

Only children 8 to 17 years of age and their parents (103 dyads) were included in child/parent concordance analyses because Likert scales were the same for both child and parent instruments, whereas they differed on instruments for the younger children; demographics are presented in Table 1. Inclusion criteria for injured children were that they were seen in one of two pediatric emergency departments or the level I trauma center in northeast Florida for a traumatic injury and had a total length of hospitalization of less than 24 hours. For all groups, at least one parent or guardian had to be able to speak, read, and write in English, and the family needed to have a working telephone. A priori power analysis using G*Power 3.0.1 software (Faul, Erdfelder, Lang, & Buchner, 2007) and anticipated participation rates determined sample size. Approval was received from Institutional Review Boards at both involved institutions prior to initiation of the study. All parents signed consent for their own and their child's participation; all children signed assent. Permission to repeat the questionnaire was requested prior to each telephone interview.

BOX. World Health Organization recommended definition of mild traumatic brain injury

Acute nonpenetrating injury caused by external forces to the head
Glasgow Coma Score 13-15 upon presentation to a health care provider or 30 minutes postinjury, whichever occurred later
At least one neurologic deficit:

- Loss of consciousness ≤ 30 minutes
- Post-traumatic amnesia ≤ 24 hours
- Disorientation or confusion
- Transient neurological symptoms (e.g., seizures, other focal neurological signs, or a nonoperative intracranial lesion)

Note. Adapted from Carroll et al., 2004.