SCIENTIFIC ARTICLE

Parental Assessment of Status of Congenital Upper Limb Differences: Analysis of the Pediatric Outcomes Data Collection Instrument

Lindley B. Wall, MD,*† Tony Shen, BS,*† Summer Roberts, MA,*† Charles A. Goldfarb, MD*†

Purpose To determine the range of the Pediatric Outcomes Collection Instrument (PODCI) scores for children with a wide variety of congenital upper limb differences and to examine the scoring effect of the patient's surgical history, family history, severity of involvement, and syndromic associations.

Methods We reviewed the PODCI scores for 109 patients, aged 2−18 years, treated for non-traumatic upper extremity conditions. Charts were reviewed for sex, age, extent of limb involvement, laterality, family history, surgical history, and syndrome association. All patients were classified based on the Oberg, Manske, Tonkin classification with general categories of malformation, deformation, or dysplasia.

Results Of 109 patients, 80 (73%) had a malformation, 12 (11%) had a deformation, and 17 (16%) had a dysplasia. The cohort as a whole had a happiness PODCI score that was similar to the normal population, yet a lower (worse) PODCI score for upper extremity and global function. Patients with a dysplasia had a higher upper extremity function scores than those with malformations or deformations, but they had similar happiness and global function scores. Complete upper limb involvement and lower extremity involvement statistically lowered the PODCI score within our study cohort, whereas a positive family history and syndromic association increased PODCI scores.

Conclusions This study showed that there was a similar level of perceived happiness between children/adolescents with congenital upper extremity conditions compared with the normal pediatric population based on PODCI scores. In contrast, the perceived upper extremity and global function was significantly decreased in patients with congenital differences compared with normal individuals. This investigation also revealed that the extent of upper extremity involvement, lower extremity involvement, family history, and syndromic association may affect PODCI scores as independent variables and should be taken into consideration in studies of upper extremity congenital anomalies. *(J Hand Surg Am. 2016;41(3):381−386.* *Copyright © 2016 by the American Society for Surgery of the Hand. All rights reserved.)*

Type of study/level of evidence Prognostic IV.

Key words Congenital, pediatric, PODCI, outcomes, upper extremity.

*From the *Shriner's Hospital for Children in St. Louis, and the †St. Louis Children's Hospital at Washington University School of Medicine, St. Louis, MO.*

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Corresponding author: Lindley B. Wall, MD, Department of Orthopaedic Surgery, Washington University, 660 S. Euclid Ave, St. Louis, MO 63110; e-mail: wallli@wudosis.wustl.edu.

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Congenital upper limb differences affect approximately 5 to 20 in 10,000 live births.[1,2] These conditions vary notably in clinical presentation and management. Recently, a classification system developed by Oberg, Manske, and Tonkin (OMT) was adopted by the International Federation of Societies for Surgery of the Hand.[3] This classification, in contrast to the Swanson classification,[4] was developed based on the current understanding of developmental biology, embryology, and genetics. The OMT classification categorizes congenital differences as malformations, deformities, or dysplasia.[5] Malformations are defined as conditions resulting from a failure in the development of limb formation or differentiation. Deformities describe conditions resulting from a disruption of an already formed limb. Dysplasias are conditions grouped based on appearance and have a known associated cellular atypia or tumor formation. The OMT was designed to adapt to the advancements in our understanding of embryology, and the International Federation of Societies for Surgery of the Hand recommends that the classifications be revisited every 3 years.

Given the complexity and variability of congenital upper limb differences, a systematic and standardized measurement of function and outcome would hold major clinical value. The Pediatric and Adolescent Outcomes Data Collection Instrument (PODCI) was developed by the Pediatric Orthopedic Society of America and the American Academy of Orthopedic Surgeons as a tool for assessing functional outcome for a variety of musculoskeletal disorders in children.[6] The PODCI is a validated questionnaire that assesses a child's overall health, pain, and ability to participate in light and vigorous activities.[7] The PODCI assesses the child's or adolescent's condition in 8 specific scales: upper extremity (UE) and physical function, transfer and basic mobility, sports/physical functioning, pain/comfort, treatment expectations, happiness, satisfaction with symptoms, and global functioning. The questionnaire is completed by the parent for children aged 2−18 and serves as a measure of parental perception of a child's function; there is also a questionnaire completed by adolescents themselves (not used in this study). A previous study of children with surgically corrected hand deformities used a different assessment tool and demonstrated that clinical severity does not necessarily correlate with the perceived impact of the hand difference.[8] Thus, a better understanding of patient (or parent) perception for upper limb differences would be valuable.

Previous studies have characterized PODCI scores for patients with specific UE conditions, including brachial plexus birth palsy, arthrogryposis, hand/wrist injury, and unilateral UE deficiency.[9−12] These studies consistently demonstrated lower PODCI scores in children with UE disorders compared with normal. However, the perceived impact for a broad range of congenital UE differences is unclear. The purpose of this study was to determine the PODCI scores for children with a wide range of diagnoses and to examine the effect of the surgical history, family history, severity of involvement, and syndromic associations on the PODCI score. We hypothesized that children with more severe limb involvement, extended surgical history, negative family history, and syndromic association would demonstrate a lower perceived outcome as measured by the PODCI.

METHODS

The PODCI questionnaire has been given to the parents of all patients undergoing upper limb surgery for congenital differences at the St Louis Shriner's Hospitals for Children since 2007. We used only the parent-completed PODCI scores for both the child and adolescent cohorts. Between 2007 and 2015, there were a total of 288 treated patients over the age of 2 years, but only 186 PODCI scores were located within the medical records. Of these there were 111 fully completed parent PODCI questionnaires of patients aged 2−18 years. Parent PODCI, not child PODCI, was used to be consistent across ages. We excluded patients treated before the age of 2 years and those with an incomplete questionnaire. For patients with multiple PODCI questionnaires reflective of multiple surgeries, only the first valid PODCI was scored. This was chosen for consistency and to assess each child only once. One patient was excluded because of concurrent diagnosis of cerebellar agenesis and another because of the preoperative diagnosis of an UE difference that was complicated by osteomyelitis. The remaining 109 patients with a completed questionnaire were included in the study.

After institutional review board approval was obtained, the medical charts were reviewed and the PODCI questionnaires were assessed. We recorded all relevant diagnoses as well as sex, age, adopted or natural born, extent of upper limb involvement (hand plate vs entire limb, as defined by the OMT classification), laterality, presence of lower limb involvement, family history, and surgical history. The PODCI domains of UE function, happiness, and global function were assessed in this study, as we felt that they were the most pertinent to this population.

For analysis, the study cohort PODCI scores were compared with previously published normal values

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