

Comparison of Self-Reports and Parent Proxy-Reports of Function and Quality of Life of Children with Below-the-Elbow Deficiency

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Background: The agreement between children's self-reports and parent proxy-reports has not been established for function and quality-of-life measures for children with musculoskeletal diagnoses, including unilateral congenital below-the-elbow deficiency. Factors influencing parent-child agreement in this population have yet to be determined.

Methods: Ten hospitals administered the Pediatric Outcomes Data Collection Instrument (PODCI) and the Pediatric Quality of Life Inventory (PedsQL) prospectively to children and adolescents with a unilateral congenital below-the-elbow deficiency in order to assess their function and quality of life. Two-thirds of the subjects wore a prosthesis. These children's and adolescents' self-reports were compared with their parents' proxy-reports for the PODCI (n = 179) and the PedsQL (n = 364).

Results: Parents underestimated their children's/adolescents' self-report scores for the upper extremity physical function domain of the PODCI ($p < 0.001$) and overestimated the scores for comfort in the pain/comfort domain of the PODCI ($p < 0.05$). Parents also reported a lower social functioning score on the PedsQL than did the children and adolescents ($p < 0.001$). Greater agreement with regard to the social functioning domain of the PedsQL was observed between parents and children than between parents and adolescents ($p < 0.05$) and between parents and subjects who did not wear a prosthesis than between parents and subjects who wore a prosthesis ($p < 0.01$).

Conclusions: Although the absolute differences are small, children with a unilateral congenital below-the-elbow deficiency report better upper-extremity function and quality of life than their parents perceive, but they may also be experiencing more pain. Factors influencing parent-child agreement on measures of quality of life include age and use of a prosthesis. Parents' reports of function may provide a helpful counterbalance to children's and adolescents' reports, but because quality of life is subjective by nature, the child's or adolescent's report is the gold standard. As a result of variability in agreement, PODCI and PedsQL parent reports cannot be considered true proxies for the self-reports of children or adolescents with unilateral congenital below-the-elbow deficiency or, possibly, of those with other musculoskeletal diagnoses.

Function and health-related quality of life are important measures of the outcomes of orthopaedic treatment. Although well-validated instruments such as the Pediatric Outcomes Data Collection Instrument (PODCI)¹ and the Pediatric Quality of Life Inventory (PedsQL)² have emerged to measure these parameters in children, there has been little research comparing parents' and children's responses in the orthopaedic setting.

By evaluating quality of life, clinicians gain insight into the impact of a disease². Because quality of life is inherently

subjective, self-reporting is preferred, but when the target population is too young or too ill to respond, parent proxy-reports are administered^{3,4}.

While some studies of chronically ill children have demonstrated low concordance between the quality-of-life measures reported by parents and those reported by their children⁵⁻⁹, others have shown moderate-to-high agreement^{3,10,11}. A similar range of low¹² to moderate/high agreement^{10,11,13,14} has been observed in healthy populations. In cases of imperfect concordance between parents' and children's re-

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TABLE I Domains of the PODCI and PedsQL

PODCI
Upper extremity physical function
Transfers/basic mobility
Sports/physical function
Pain/comfort
Happiness
Global function
PedsQL
Physical health
Emotional functioning
Social functioning
School functioning
Psychosocial health
Total scale score

ports, parents tend to underestimate the quality of life of chronically ill children^{10,15-17} and overestimate that of healthy children¹³, and parents provide more concordant information about children younger than twelve and less concordant information about adolescents¹⁸. Differences between self-reports and proxy-reports are termed “cross-informant variance.”¹¹

Parent-child concordance regarding the child’s quality of life has not been well studied for children with musculoskeletal conditions. Use of the Child Behavior Checklist to study behavioral and emotional problems of children and adolescents with congenital limb deficiencies indicated that parents under-identify problems such as depression, anxiety, and withdrawal⁷. However, that study has not been replicated with use of the better-validated PedsQL.

While parent-child concordance regarding the child’s quality of life has been reported for selected populations, it has not been studied with regard to children’s level of function, even though parents’ reports are often used to measure the functional status of children. Parent-child concordance in their responses to the PODCI has not yet been studied, although PODCI scores have been reported for children with congenital conditions such as congenital scoliosis¹⁹ (who had lower scores for comfort in the PODCI pain/comfort domain as compared with the general population) and those with unilateral upper-extremity deficiencies²⁰ (parents reported significantly lower-than-“normal” scores for several PODCI domains). Cross-informant variance in PODCI scores has not been measured for children with unilateral congenital below-the-elbow deficiency, to our knowledge. Furthermore, factors influencing parent-child agreement on all domains of the PODCI have yet to be established.

Studies of cross-informant variance may have a wider application because parent proxy-reports may predict how the general population views children with musculoskeletal conditions. Furthermore, since a previous study of this same population showed that children with unilateral congenital below-the-elbow deficiency did not differ significantly from

the general population in terms of their scores on the PedsQL (for all ages) or PODCI (for subjects eleven years of age and older)²¹, the findings of the present study may also have more general applications.

Materials and Methods

Information collected from 489 children and adolescents with a unilateral congenital below-the-elbow deficiency and their parents was reviewed. Subjects and parents were recruited at ten participating hospitals; 55% of the subjects surveyed were female, and 66% chose to wear a prosthesis. The testing protocol, established by the UCED (Unilateral Congenital Below-the-Elbow Deficiency) Study Group (see Note at the end of the paper), included administration of the PedsQL and the PODCI as measures of quality of life and function, respectively. The protocol was approved by eleven institutional review boards. The impact of prosthesis use on function and quality of life in this population of children has previously been reported²¹. The PedsQL and PODCI tests were administered in a touch-screen computer format and were offered in an English-language version as well as in Spanish and French.

The PedsQL survey was administered in parallel child-self-report and parent-proxy-report formats. The instrument consists of twenty-three questions and four generic core scales (physical health, emotional functioning, social functioning, and school functioning) designed to assess a child’s health-related quality of life (Table I). The psychosocial health domain score is an average of the emotional, social, and school functioning scores, and the total scale score is an average of the scores on all four generic core scales. A scoring algorithm translates the responses “never,” “almost never,” “sometimes,” “often,” or “almost always” into numerical results of 0%, 25%, 50%, 75%, and 100%, respectively, with higher numbers indicating better health-related quality of life². The reports for

TABLE II Demographic Characteristics of Patients

Variable	PODCI* (no.)	PedsQL (no.)
Total	179	364
Sex		
Male	77	161
Female	102	203
Prosthesis use		
Yes	116	245
No	63	119
Age		
<12 yr		199
≥12 yr		165

*There was a total of 104 parent-adolescent responses for the sports/physical function domain of the PODCI; fifty subjects were male, fifty-four were female, sixty-two wore a prosthesis, and forty-two did not wear a prosthesis.

TABLE III Comparison of PODCI and PedsQL Scores Between Parent Proxy-Reports and Child/Adolescent Self-Reports

Domain	No.	Mean Score		Mean Difference	P Value (Paired t Test)
		Child/Adolescent	Parent		
PODCI					
Upper extremity physical function	179	96.3	93.9	-2.4	<0.001
Transfers/basic mobility	179	98.9	98.7	-0.2	0.28
Sports/physical function	104	93.3	93.4	0.1	0.90
Pain/comfort	179	89.5	92.4	2.9	<0.05
Happiness	179	87.6	86.2	-1.4	0.24
Global function	104	94.4	94.5	0.1	0.85
PedsQL					
Physical health	364	88.6	87.8	-0.8	0.22
Emotional functioning	364	77.7	76.1	-1.6	0.11
Social functioning	364	83.1	80.0	-3.1	<0.001
School functioning	364	49.6	50.6	1.0	0.36
Psychosocial health	364	79.9	78.7	-1.2	0.10
Total scale score	364	82.9	81.9	-1.0	0.08

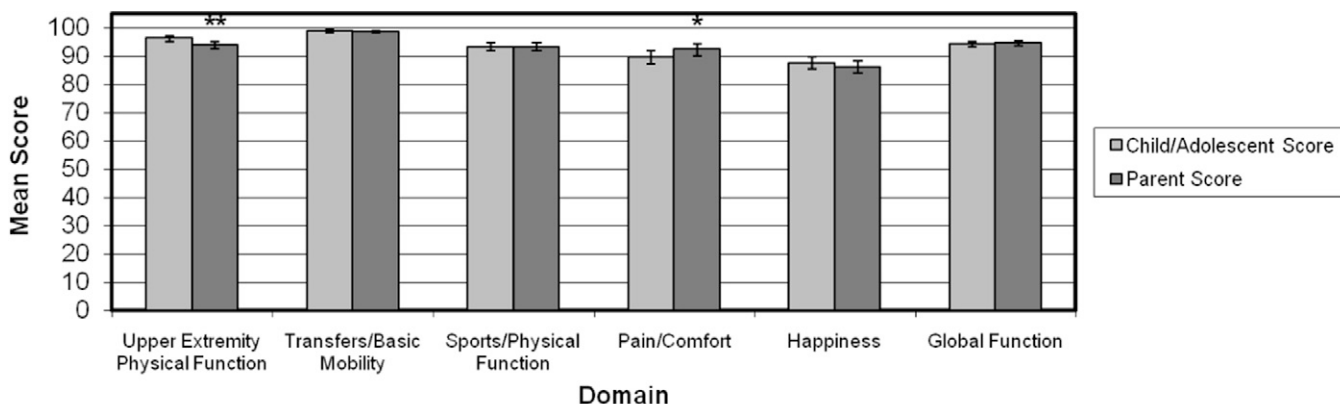
children two to four years of age are provided exclusively by the parents, whereas both parent and child reports are available for children over the age of four.

The PODCI consists of 108 questions and six validated domains (upper extremity physical function, transfers/basic mobility, sports/physical function, pain/comfort, happiness, and global function) designed to assess musculoskeletal health and functionality (Table I). Global function is a combined measure of upper extremity physical function, transfers/basic mobility, sports/physical function, and pain/comfort. Outcome scores range from 0 to 100 for each domain, with higher scores indicating better outcomes; scores above the mid-80s are considered to represent normal function^{1,22}.

The PODCI instrument is designed to allow children eleven years of age and older to self-report. One hundred and ninety-one

adolescents between the ages of eleven and twenty years completed the PODCI survey. There was no corresponding parent report for twelve of these subjects, who were consequently not included in the analysis. As a result, 179 parent-adolescent paired responses were included for the upper extremity physical function, transfers/basic mobility, pain/comfort, and happiness domains. One hundred and four parent-adolescent responses were included for the sports/physical function domain of the PODCI because seventy-five responses were either not completed or did not have a corresponding report.

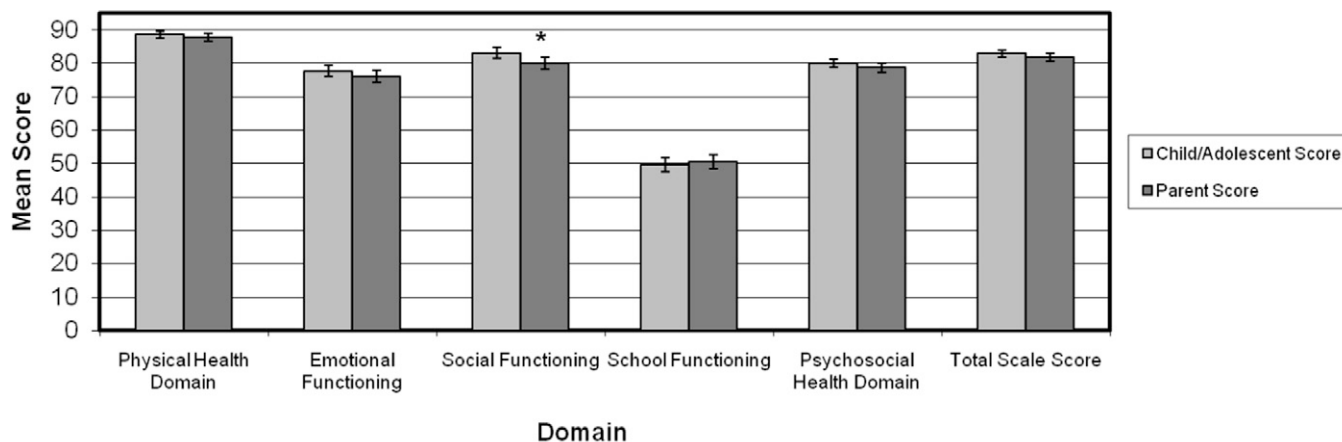
Three hundred and seventy-two subjects between the ages of three and twenty years and 478 parents completed the PedsQL survey. Of these reports, 114 were excluded from the analysis because there was not a corresponding parent or child report. This was largely due to the PedsQL



* Denotes statistically significant differences at * $p < 0.05$, ** $p < 0.01$

Fig. 1

Mean differences between parent and child/adolescent PODCI scores. The I bars indicate 95% confidence intervals.



*Denotes a statistically significant difference at $p < 0.001$

Fig. 2

Mean differences between parent and child/adolescent PedsQL scores. The I bars indicate 95% confidence intervals.

administration protocol, which dictates that only the parent respond for children two to four years of age. A total of 364 matching parent-child responses on the PedsQL were therefore included in the study. The total population size for each domain of the PODCI and PedsQL is listed in Table II.

The mean difference between the parent and subject responses in the individual health domains of the PedsQL and PODCI was calculated, and a two-tailed paired t test was used to evaluate the results with a significance criterion of $p < 0.05$. Average differences between parent and child or adolescent responses were calculated by subtracting the child's or adolescent's score from the parent's score, with a negative difference indicating that the parent's score was lower than the corresponding child's or adolescent's score.

To assess the effect of age, sex, and prosthesis use on parent-child agreement, a two-tailed paired t test was used to compare the absolute mean difference between the parent and child responses for each factor with a significance criterion of $p < 0.05$. In addition, cross-informant variance was analyzed with two-way mixed-effect-model (absolute agreement, single measure) intraclass correlations for parents and children for each domain of the PODCI and PedsQL¹¹. An intraclass correlation coefficient of ≤ 0.40 was considered to indicate poor-to-fair agreement; 0.41 to 0.60, moderate agreement; 0.61 to 0.80, good agreement; and 0.81 to 1.00, excellent agreement.

The subjects who completed the PedsQL were classified, by age, as children (less than twelve years of age; $n = 199$) or adolescents (twelve years of age or older; $n = 165$). Children begin self-reporting at the age of eleven years according to the PODCI administration protocol and at the age of five years according to the PedsQL protocol. As a result, it is not possible to assess the agreement between the parents and children (less than twelve years old) for the PODCI²³. Parent-child pairings were also divided according to sex (seventy-seven males and 102 females for the PODCI, fifty males and fifty-four females for the sports/physical function domain of the

PODCI, and 161 males and 203 females for the PedsQL) and according to prosthesis use (116 who responded to the PODCI wore a prosthesis and sixty-three did not, sixty-two who responded to the sports/physical function domain of the PODCI wore a prosthesis and forty-two did not, and 245 who responded to the PedsQL wore a prosthesis and 119 did not) (Table II).

Source of Funding

This study was funded by a grant from Shriners Hospitals for Children.

Results

Overall Agreement in Mean Scores

Parents of children and adolescents with a unilateral congenital below-the-elbow deficiency underestimated the subjects' self-report scores for the upper extremity physical function domain of the PODCI ($p < 0.001$) and overestimated the scores for comfort in the pain/comfort domain of the PODCI ($p < 0.05$) (Table III) (Fig. 1). Parents underestimated their child's or adolescent's self-report scores for the social functioning domain of the PedsQL ($p < 0.001$) (Fig. 2).

Agreement in Mean Scores for Subpopulations

Table IV demonstrates the mean differences between parent proxy-reports and child or adolescent self-reports of the PODCI and PedsQL scores by age, sex, and prosthesis use. Parents of adolescents (twelve years old or more) underestimated the self-report scores for the social functioning domain of the PedsQL ($p < 0.001$). The absolute mean difference in the scores for this domain between the parents and the adolescents was greater than the absolute mean difference between the parents and the children (less than twelve years old) ($p < 0.05$). Significant differences were also observed between the parents and the adolescents with regard to the score for the psychosocial health domain and the total scale

TABLE IV Comparison of PODCI and PedsQL Scores Between Parent Proxy-Reports and Child/Adolescent Self-Reports by Sex, Prosthesis Wear, and Age

Domain	Parents and Children <12 Yr Old		Parents and Adolescents ≥12 Yr Old		Parents and Males		Parents and Females		Parents and Subjects Who Wore Prosthesis		Parents and Subjects Who Did Not Wear Prosthesis	
	Mean Difference	P Value	Mean Difference	P Value	Mean Difference	P Value	Mean Difference	P Value	Mean Difference	P Value	Mean Difference	P Value
PODCI												
Upper extremity physical function					-1.17	0.14	-3.32	<0.01	-2.06	<0.05	-3.02	<0.01
Sports/physical function					0.24	0.81	-0.04	0.98	-0.16	0.87	0.47	0.71
Pain/comfort					5.30	<0.01	1.16	0.50	2.68	0.06	3.43	0.14
Global function					1.08	0.13	-0.77	0.44	-0.07	0.95	0.35	0.75
PedsQL												
Physical health	-0.30	0.73	-1.32	0.12	-1.09	0.23	-0.44	0.61	-1.15	0.10	0.12	0.91
Social functioning	-1.11*	0.40	-5.54*	<0.001	-2.50	0.06	-3.72	<0.01	-4.93†	<0.001	0.48†	0.79
Psychosocial health	-0.13	0.89	-2.40	<0.05	-1.09	0.29	-1.25	0.20	-1.89	<0.05	0.22	0.86
Total scale score	-0.27	0.74	-1.97	<0.05	-1.12	0.20	-0.99	0.23	-1.69	<0.05	0.16	0.88

*Greater agreement with regard to the social functioning domain of the PedsQL was observed between parents and children than between parents and adolescents ($p < 0.05$). †Greater agreement with regard to the social functioning domain of the PedsQL was observed between parents and subjects who did not wear a prosthesis than between parents and subjects who wore a prosthesis ($p < 0.01$).

score of the PedsQL ($p < 0.05$). Parents and children (less than twelve years old) did not differ significantly with regard to scores for any domain of the PedsQL.

Parents of male subjects overestimated the self-report scores for comfort in the pain/comfort domain of the PODCI ($p < 0.01$), whereas parents of female patients underestimated the self-report scores for the upper extremity physical function domain of the PODCI ($p < 0.01$) and the social functioning domain of the PedsQL ($p < 0.01$). No significant difference was observed when the absolute mean difference between parents and male subjects was compared with the absolute mean difference between parents and female subjects.

Parents underestimated the scores for the upper extremity physical function domain of the PODCI as self-reported by both the subjects who wore a prosthesis ($p < 0.05$) and those who did not ($p < 0.01$). The parents of the subjects who wore a prosthesis also underestimated the self-report scores for the social functioning domain of the PedsQL ($p < 0.001$), and the absolute mean difference in these scores between the parents and the subjects who wore a prosthesis was significantly greater than the absolute mean difference in the scores between the parents and the subjects who did not wear a prosthesis ($p < 0.01$). Significant differences were also observed between the parents and the subjects who wore a prosthesis with regard to the score for the psychosocial health domain and the total scale score of the PedsQL ($p < 0.05$).

Intraclass Correlation Coefficients (Table V)

Parents and their children or adolescents had poor-to-fair agreement on the scores for the upper extremity physical

function domain of the PODCI (intraclass correlation coefficient = 0.32) and moderate agreement for the remaining domains of that scale. They had poor-to-fair agreement on the

TABLE V Two-Way Mixed-Effect Model (Absolute Agreement, Single Measure) Intraclass Correlation Coefficients

Test and Domain	Intraclass Correlation Coefficient*
PODCI	
Upper extremity physical function	0.32
Transfers/basic mobility	0.55
Sports/physical function	0.50
Pain/comfort	0.42
Happiness	0.42
Global function	0.45
PedsQL	
Physical health	0.34
Emotional functioning	0.36
Social functioning	0.42
School functioning	0.47
Psychosocial health	0.41
Total scale score	0.41

*Intraclass correlation coefficient of ≤ 0.40 = poor-to-fair agreement, 0.41 to 0.60 = moderate agreement, 0.61 to 0.80 = good agreement, and 0.81 to 1.00 = excellent agreement.

physical health scores (intraclass correlation coefficient = 0.34) and the emotional functioning scores (intraclass correlation coefficient = 0.36) of the PedsQL, whereas the agreement for the remaining PedsQL domains was at the low end of moderate.

Discussion

This study shows that although both children with unilateral congenital below-the-elbow deficiency and their parents report upper-extremity function in the normal range and high social functioning, the children report better upper-extremity function and social functioning than their parents perceive and they may also be experiencing more pain.

Age and prosthesis use influence parent-child agreement on the PedsQL, but sex and prosthesis use do not influence parent-child agreement on the PODCI. Since children under the age of eleven do not self-report on the PODCI, it was not possible to compare the PODCI function scores between parents and children under that age.

While agreement between parent and child reports of quality of life has been studied in pediatric populations with various health problems, little research has focused on children with congenital deficiencies and musculoskeletal conditions. Our study shows that the previously reported tendency for parents to underestimate the quality of life of their children^{10,16} is also exhibited by parents of children or adolescents with unilateral congenital below-the-elbow deficiency. These small but statistically significant differences may be due to the adjustments children with congenital deficiencies make to adapt to their environment²⁴. These differences could also be due to the children's lack of awareness of a health status that is different from the one defined by their condition. Similarly, parents may perceive that their child has more functional and social limitations because they only know a state of health that does not involve a congenital deficiency. Although psychological problems such as stress, anxiety, and depression may affect test scores, they are not directly measured by the PODCI or PedsQL.

Despite the utility and wide acceptance of the PODCI as a tool to assess musculoskeletal function, the agreement between parent and child responses to this instrument has not been studied, to our knowledge. The finding that children with unilateral congenital below-the-elbow deficiency report lower scores for comfort than do their parents is consistent with previous findings in a population of children with congenital scoliosis, who reported lower scores for comfort than did the general population¹⁹. A similar study of PODCI scores in a population of children with unilateral upper-extremity deficiency showed that parents report lower-than-"normal" scores for the upper extremity physical function domain²⁰. Our study suggests that this may be due in part to parents underestimating their child's upper-extremity function.

Varni et al. evaluated the PedsQL with regard to its sensitivity, responsiveness to change, and impact on clinical decision-making²⁵ as well as its cross-informant variance between children and parents²⁶. They found that this instrument

was sensitive to disease severity and responsive to change in the subject's condition and that the intraclass correlation coefficients for the agreement between child and parent reports ranged from 0.36 to 0.50. Our findings were comparable, with intraclass correlation coefficients of between 0.32 and 0.55 for the PODCI and between 0.34 and 0.47 for the PedsQL. Correlation between parent and child reports was poor to fair for the PODCI upper extremity physical function domain and the PedsQL physical health and emotional functioning scores. The parent-child correlations were moderate for the other five PODCI domains and the four remaining PedsQL domains, but none of the domains of either of the tests showed good or excellent parent-child agreement. We agree with Varni et al.²⁵ that measuring the perspectives of both the parent and the child is important. Varni et al. also pointed out that, although patient self-report is the standard for measuring health-related quality of life, it is the parent's perception of their child's health-related quality of life that influences health-care utilization. An additional perspective to consider may be that of the health-care provider. A recent study showed that health-care providers' assessments of the quality of life of children with heart disease differ from those of the children and parents²⁷.

Our study suggests that the age of the subject affects the agreement between parent proxy-reports and child or adolescent self-reports of quality of life. In a study of the quality of life of patients with cancer, Chang and Yeh¹⁸ found that parent proxy-reports were more valid for children who were less than twelve years old than they were for adolescents. Our results support this finding, with parents and children providing more concordant PedsQL social functioning scores than parents and adolescents ($p < 0.05$ for the difference between absolute mean differences between the groups). Since scores in the social functioning domain are factored into scores for the psychosocial health domain and the total scale score, it is not surprising that significant differences were also observed between parents and adolescents for these two domains.

Our finding that parents underestimate self-report scores for the upper extremity physical function domain was consistent regardless of whether or not the child wore a prosthesis, suggesting that children with unilateral congenital below-the-elbow deficiency may have better upper-extremity function than their parents perceive regardless of prosthesis use. Since no discrepancy was observed between the absolute difference in the PODCI scores between the parents and subjects who wore a prosthesis and the absolute difference in the PODCI scores between the parents and the subjects who did not wear a prosthesis, our study suggests that prosthesis use does not influence parent-child agreement on measures of function. However, prosthesis use influenced parent-child agreement on the scores for the social functioning domain of the PedsQL, with parents of subjects who wore a prosthesis underestimating the self-report scores to a greater degree than parents of subjects who did not wear a prosthesis. This suggests that use of a prosthesis alters how parents, and perhaps even the general population, view the social functioning and quality of life of children with unilateral congenital below-the-elbow deficiency. While a previous study

of this same population showed that the use of a prosthesis did not influence the reported quality of life²¹, our findings suggest that prosthesis use may influence how a parent views and subsequently reports the quality of life of a child with unilateral congenital below-the-elbow deficiency.

This study had several limitations. First, absolute differences between parent and child responses were small, raising the question of whether the significant differences that were found were actually clinically relevant. The concept of clinical relevance has not been applied to previous studies comparing child and parent proxy-reports, although it is definitely helpful to clinicians comparing function and quality of life before and after treatment or comparing normal and diseased populations. While the impact of a change in the PedsQL score on clinical decision-making has been examined^{25,26}, we do not know if the concepts of a score changing over time or differences in scoring between populations can be applied to a comparison of two individuals' perception of the same phenomenon. Although several of the small differences that we described between large populations of children and parents are significant, we do not know if they are clinically relevant, despite their agreement with the findings of some previous comparisons of child and parent proxy-reports in other patient populations^{10,15-17} and their generally consistent low intraclass correlation coefficients.

In addition, both the child-self-report and the parent-proxy PODCI scores clustered at the high end of the scale, which is referred to as a *ceiling effect*. Data with a ceiling effect have restricted variability, which limits the likelihood of finding a significant correlation. Haynes and Sullivan proposed that PODCI scores above the mid-80s represent normal-range function and that the PODCI is not sensitive to change in normally functioning children¹. However, we did not attempt to measure change in this study; instead, we focused on differences in perception between parents and children regarding the child's functional status. We do not know the impact of the ceiling effect on this comparison.

Our study supports previous findings that parents have a tendency to underestimate their child's quality of life^{10,15-17}

and provides evidence that this trend is applicable to children with a congenital deficiency. Parents may underestimate the function and overestimate the comfort of children with a unilateral congenital below-the-elbow deficiency. These findings may provide clinicians with insight into how parents of children with other musculoskeletal conditions perceive the quality of life and function of their child and how factors such as age can affect parent-child agreement on measures of quality of life. The differences that we observed between parents' and children's responses on the PedsQL and the PODCI indicate that both parents and children should respond to these instruments whenever possible. Furthermore, since the same population of children with a unilateral congenital below-the-elbow deficiency reported PODCI and PedsQL scores similar to those in the general population in a previous study²¹, these results may be applicable to the general population as well. ■

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