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RESEARCH ARTICLE

Longitudinal validation of the Caregiver Priorities and Child Health Index of Life with Disabilities in a Dutch sample of nonambulatory children with severe disabilities

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Abstract

Background: The purpose of this study was to evaluate the longitudinal validity of the Dutch version of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD), a health-related quality of life instrument for nonambulatory children with severe motor disabilities and accompanying disorders.

Methods: The effect of two interventions, Botox injections in the hip region and percutaneous endoscopic gastrostomy, was followed over time. Caregivers ($n = 38$) of nonambulatory children (26 boys, 12 girls; mean age: 9 years, 5 months [4 years, 9 months]) with severe disabilities completed the questionnaire prior to the intervention, at 3 months and 6 months follow up. Seven a priori hypotheses were formulated. Longitudinal validity was analysed by a paired t test of the pre-post scores and correlation analysis between the change-scores and two external criteria: a caregivers' perceived change in health-related quality of life of the child questionnaire and a general health-related quality of life instrument.

Results: The results reported here follow completely the pattern we hypothesized for four analyses and partially in the remaining three. In the Botox group, the mean change-score at 3 months was 6.9 points ($p < 0.05$), which exceeds the minimal clinically important difference of 5.8 points. At 6 months, the effect was diminished to 4.5 points, in line with the temporary effect of Botox. There were moderate positive correlations between the change-scores and an external criterion (Spearman's rho: 0.46–0.58).

Conclusions: This study indicates that the CPCHILD Dutch version has sufficient longitudinal validity statistically and clinically in nonambulatory children with severe disabilities.

KEYWORDS

cerebral palsy, health-related quality of life, nonambulatory children, responsiveness, severe disabilities

1 | INTRODUCTION

Health-related quality of life has been recognized as a key component to assess in children with severe motor disabilities due to cerebral palsy (Bjornson & McLaughlin, 2001) or other causes. The Gross Motor Function Classification System describes the functional abilities in mobility and distinguishes five levels of impairment (Gross Motor Function Classification System, 2015). Levels IV and V represent the nonambulatory children (Reid, Carlin, & Reddihough, 2011). Their motor disorders are often accompanied by disturbances of sensation, cognition, communication, perception, behaviour, and/or a number of related health conditions. These children experience difficulties with their activities in daily life, communication, mobility, and their health in such a way that they depend on their caregivers for the main part of their daily needs (Narayanan et al., 2006). This group of nonambulatory children with severe disabilities are often subject to interventions, such as Botox injections or surgery, to preserve or improve their comfort, well-being, ease of caregiving, and quality of life. It is therefore important to measure the effectiveness of these interventions on the quality of life of the child and to have a valid instrument that is sensitive to change over time. The Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) is a validated health-related quality of life proxy measure specifically developed for nonambulatory children with severe disabilities (Narayanan et al., 2006). In this target group, a proxy measure, where the parent completes the form about the child, is nearly always necessary due to communicative and/or cognitive disabilities of the child. The items of this questionnaire are in line with the motor and intellectual abilities of this target group and cover all domains of health-related quality of life. A systematic review showed that the CPCHILD is a health-related quality of life instrument for children with severe disabilities with strong psychometric properties (Carlou et al., 2010). The CPCHILD covers a variety of activity and participation categories of the International Classification of Functioning Children and Youth version from the chapters communication (d3), mobility (d4), self-care (d5), major life areas (d8), and community, social, and civil life (d9) as well as several categories from the body function and environmental factors (Schariti, Fayed, Cieza, Klassen, & O'donnell, 2011).

In a previous study, we made a transcultural adaptation of the CPCHILD into a Dutch version (CPCHILD-DV), and we established the reliability and construct validity of this instrument (Zalmstra et al., 2015). In order to evaluate effects of interventions over time, the sensitivity to change—or responsiveness—needs to be evaluated and that is the topic of this study. Responsiveness is defined by the COSMIN panel as “the ability of an instrument to detect change over time in the construct to be measured.” Nowadays, responsiveness is regarded as a form of longitudinal validity and is to be tested likewise with a priori hypotheses and external criteria (Terwee, Dekker, Wiersinga, Prummel, & Bossuyt, 2003). As an external criterion for change in quality of life, a caregivers' perceived change in health-related quality of life of the child questionnaire was developed, in which the primary caregiver will rate whether his/her child's quality of life in several domains has improved, worsened, or remained the

Key messages

- Changes in the CPCHILD-DV scores reflect expected changes related to the temporary effect of Botox on health-related quality of life in nonambulatory children with severe disabilities.
- The CPCHILD-DV can be used as an evaluative instrument of health-related quality of life in nonambulatory children with severe disabilities.

same in the past period. An additional external criterion can be another health-related quality of life instrument. Because there is no other condition-specific valid instrument available for nonambulatory children with severe disabilities, one has to use a more generic health-related quality of life instrument.

The main purpose of this study is to assess whether the CPCHILD-DV has sufficient longitudinal validity to be used as an outcome measure in nonambulatory children with severe disabilities. Because the CPCHILD-DV is a multidimensional instrument, we aimed to follow two kinds of interventions that are fairly common in this target group and that may influence different domains: Botox injections in muscles of the hip region (with an aim of reducing pain or enhance ease of care) and, second, placing a percutaneous endoscopic gastrostomy to provide a means of feeding when oral intake is not adequate. On the basis of the previous evidence of the effects of these intervention, we produced seven hypotheses of how we expected quality of life measures to change in children who undergo the interventions.

1. The intervention groups will show a significant larger change-score than the non-intervention group.
2. The group with Botox intervention will have the highest mean CPCHILD-DV score at 3 months (because of the temporary effect of Botox).
3. The group with gastrostomy tube intervention will have highest mean score at 6 months.
4. The intervention group will have a mean change-score of at least the minimal clinically important difference (the smallest change in score that is considered important to the patient; Terwee et al., 2003).
5. The CPCHILD-DV scores will show a significant larger change-score than the generic instrument.
6. The CPCHILD-DV change-score will show a significant correlation with the questionnaire scores of caregivers' perceived change in health-related quality of life of the child.
7. The CPCHILD-DV change-scores will show higher correlations with the questionnaire scores of caregivers' perceived change in health-related quality of life of the child than the generic instrument will show.

2 | METHODS

Between May 2014 and September 2016, caregivers of 38 nonambulatory children (Gross Motor Function Classification Level IV or V) with severe disabilities as a result of cerebral palsy or other severe nonprogressive disease, aged between 4 and 18 years, were recruited by several rehabilitation centres and hospitals in the Netherlands. Exclusion criteria included the presence of a progressive neurological disorder or severe concurrent illness or disease. The children with an indication for intervention who did not undergo the intervention (due to several reasons, e.g., postponement) were followed as a non-intervention group. All participating caregivers gave a written informed consent. The ethical review board at the University Medical Centre of Groningen approved the study. Measures were made at baseline prior to the intervention (A), 3 months (B) and 6 months (C) follow up. The questionnaires were sent at the home address by mail. When a questionnaire was not returned, reminders were sent by e-mail or by phone.

In this study, we used three instruments. The CPCHILD-DV is a reliable and valid proxy measure of health status and well-being of nonambulatory children with cerebral palsy (Zalmstra et al., 2015; internal consistency 0.89, intraobserver reliability ICC: 0.73, distinguishes between subgroups of motor abilities and cognitive abilities). The CPCHILD-DV consists of 37 questions across six domains: activities of daily life/personal care; positioning, transferring, and mobility; comfort and emotions; communication and social interaction; health; and overall quality of life. Each item is rated on a 6-point or 7-point scale and for some items in addition a 4-point level of assistance modifier. The questionnaire takes 20–30 min to complete. When there are more than 50% missing items (item not scored or item labelled as “not applicable”) in a domain or in the total questionnaire, no domain score or no total score can be calculated. The second instrument is a generic health-related quality of life instrument: The Pediatric Quality of Life Inventory™ (PedsQL) is a modular approach to measure health-related quality of life in healthy children and adolescents (from 2 to 18 years) and those with acute and chronic health conditions (Varni, Seid, & Kurtin, 2001; internal consistency 0.90, distinguishes between healthy children and acute and chronic health conditions). The 23-item PedsQL Generic Core Scales were designed to measure the core dimensions of health as delineated by the World Health Organization, as well as role (school) functioning. The four multidimensional scales are Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning. In general, the questionnaire takes 5 min to complete. When there are more than 50% missing items (item not scored or item labelled as “not applicable”) in a domain or in the total questionnaire, no domain score or no total score can be calculated. The third instrument was developed for this study and is a questionnaire of the caregivers' perceived change of health-related quality of life of the child because the intervention on five domains on a 5-point ordinal rating scale, from -2 (*clearly deteriorated*) to $+2$ (*clearly improved*). These last two instruments were used as external criteria.

2.1 | Statistical analysis

The mean scores of total and domain scores were compared before and after the intervention using paired t tests, and growth curves were made to visualize the change-scores. Correlation analyses were performed to compare the change-scores of the CPCHILD-DV and of the PedsQL with the scores of the caregivers' perceived change questionnaire, using the Spearman's rank correlation coefficient. Spearman's rho between 0.30 and 0.50 are considered low, between 0.50 and 0.70 moderate, and between 0.70 and 0.90 are considered high. The significance level is set at 0.05. For the interpretation of the change-scores, it is important to define in advance the minimal clinically important difference, the smallest change in score that is considered important to the patient (8). In most circumstances, the threshold of discrimination for changes in health-related quality of life instruments for chronic diseases appears to be approximately half a standard deviation (SD) of the mean score (Norman, Sloan, & Wyrwich, 2003). In our first validation study, the SD of the mean CPCHILD-DV score was 11.5 points (Zalmstra et al., 2015). The minimal clinically important difference is therefore beforehand estimated as 5.8 points. Sample size calculations indicated that a difference in the mean of the change-score of 5.8 points could be statistically detected with a paired t test (at $p < 0.05$ and a power of 80%) with $n = 33$. With the same sample size, a correlation coefficient of at least 0.50 could be statistically detected using a Fisher's z test for a Spearman correlation coefficient different from zero under the same study reliability requirements.

3 | RESULTS

Table 1 shows the characteristics of the children and their caregivers. The CPCHILD-DV questionnaire has a normal distribution with no floor effects. There are 38 CPCHILD-DV questionnaires returned at the first measure point, 35 at the second, and 31 at the last measure point. Due to missing scores, no total score could be calculated for 4% of the CPCHILD-DV questionnaires and 18% of the PedsQL questionnaires. In addition, it appeared that 40% of the respondents struggled with completing the PedsQL. When a question was not applicable for a child, the same parent wrote at one measure point “not applicable” and at another measure point the lowest score. This phenomena had great impact on calculating the total score, because of the amount of items that were completed (discrepancy up to 45% of the items) and therefore on the change-scores. To be able to calculate accurate change-scores, we decided for each individual participant to standardize the “not applicable” scores in all measure points.

First, we compared the total intervention group with the non-intervention group with the paired t test at the different measure points. The differences between the scores have a normal distribution. Table 2 shows that the intervention group has a significant mean change-score at 3 months (B) and at 6 months (C) compared with baseline (A). The non-intervention group has no significant mean change-score. Looking at the two intervention groups (see Table 2), the Botox

TABLE 1 Characteristics of child and caregiver

Child (n = 38)	Category	n (%)	Mean (SD)	Range
Age (years, months)			9 years, 5 months (4 years, 9 months)	3–18
Gender	Boy	26		
	Girl	12		
Diagnosis	Cerebral palsy	25 (66)		
	Cerebral disorder	3 (8)		
	Psychomotor retardation	5 (13)		
	Other	5 (13)		
School level	Day care centre	15 (39)		
	Special school	22 (58)		
	Other	1 (3)		
Intervention	Botox	21 (55)		
	Gastrostomy tube	8 (21)		
	Non-intervention	9 (24)		
CPCHILD-DV scores	Before intervention (A)	37 (97)	51.8 (13.4)	16–76
	At 3 months (B)	34 (90)	54.7 (12.5)	32–80
	At 6 months (C)	30 (79)	52.3 (12.0)	28–76
PedsQL scores	Before intervention (A)	36 (95)	51.3 (17.6)	15–100
	At 3 months (B)	32 (84)	53.6 (17.3)	29–90
	At 6 months (C)	25 (66)	57.3 (16.1)	31–96
Caregiver	Category	n (%)	Mean (SD)	Range
Age (years)			41.5 (7.1)	29–55
Gender	Mother	33 (87)		
	Father	4 (11)		
	Professional caregiver	1 (2)		
Educational level ^a	Primary	6 (16)		
	Secondary	12 (31)		
	Tertiary	19 (50)		
	Missing	1 (3)		

Abbreviations: CPOCHILD-DV, Caregiver Priorities and Child Health Index of Life with Disabilities Dutch version; PedsQL, Pediatric Quality of Life Inventory™.

^aInternational standard classification of education (2012).

group has a mean significant positive difference of 6.9 points, 3 months after the intervention. On the domain level, there are significant change-scores at two domains: activities of daily life/personal care; comfort and emotions. After 6 months, the mean score is diminished. This can be seen in Figures 1 and 2, where growth curves are displayed for each of the interventions. The gastrostomy group shows the highest positive difference of 3.8 points, 6 months after the intervention but not significant ($p = 0.23$). On the domain level, the highest change-scores are on two domains: comfort/emotions and health but not significant. The growth curve has a slight upward curve.

The change-scores of the PedsQL show more variation and have higher SD's as seen in Table 2. There is a significant change-scores for the intervention group at 3 months. On the domain level, there are no significant change-scores.

The questionnaire scores of caregivers' perceived change in health-related quality of life show at 3 months a median of +1 (*somewhat improved*) for the overall quality of life. On the domain level, there is a median of +0.5 on the domain comfort and emotions. The other domains have a median of zero. At 6 months, the overall score and all the domains have a median of zero. Table 3 shows moderate

significant correlations of the CPOCHILD-DV score with the questionnaire scores of caregivers' perceived change in health-related quality of life of the child in the domains personal care, comfort and emotions, and the total score (0.46–0.58) at 3 months (A–B). At 6 months (B–C), there are no significant correlations. The PedsQL total score shows no significant correlation at 3 months and a moderate correlation at 6 months with the questionnaire scores of caregivers' perceived change in health-related quality of life of the child. On the domain level, there is a low significant correlation in the psychosocial domain at 6 months.

4 | DISCUSSION

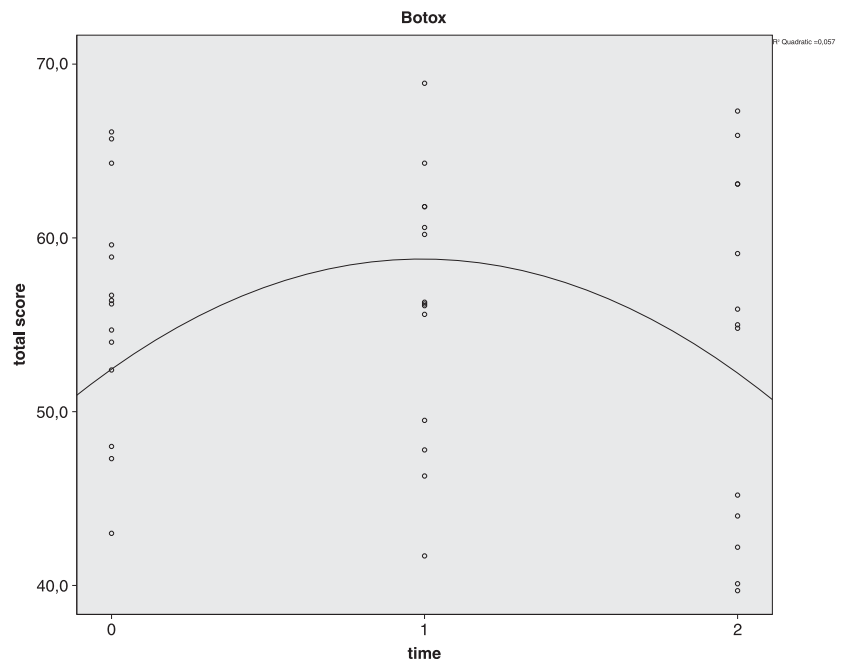
The purpose of this study was to establish whether the CPOCHILD-DV has sufficient longitudinal validity to be used as an outcome measure in nonambulatory children with severe disabilities by confirming a priori hypotheses. Looking at Table 1, the sample shows an even distribution in age, and the mean and range of the CPOCHILD-DV scores are in line with those of the validation study (Zalmstra et al., 2015).

TABLE 2 Paired *t* test for mean differences CPCHILD-DV and PedsQL

CPCHILD-DV	Mean difference at 3 months (SD)	df	<i>t</i> (p value)	Mean difference at 6 months (SD)	df	<i>t</i> (p-value)
Intervention	5.5* (8.0)	24	3.5 (<0.01)	4.3* (8.2)	20	2.4 (0.03)
Botox	6.9* (8.1)	17	3.6 (<0.01)	4.5 (8.8)	13	1.9 (0.08)
Gastrostomy	2.0 (6.7)	6	0.8 (0.47)	3.8 (7.5)	6	1.3 (0.23)
Non-intervention	-1.2 (5.7)	8	-0.6 (0.56)	1.0 (6.4)	8	0.5 (0.65)
PedsQL	Mean difference at 3 months (SD)	df	<i>t</i> (p value)	Mean difference at 6 months (SD)	df	<i>t</i> (p-value)
Intervention	4.4* (8.8)	21	2.3 (0.03)	3.2 (9.1)	16	1.5 (0.17)
Botox	4.0 (10.0)	14	1.6 (0.14)	3.2 (7.5)	9	1.4 (0.21)
Gastrostomy	5.2 (5.9)	6	2.3 (0.06)	3.2(11.8)	6	0.7 (0.50)
Non-intervention	-4.9 (9.1)	8	-1.6 (0.15)	2.4 (12.5)	6	0.5 (0.63)

Abbreviations: CPCHILD-DV, Caregiver Priorities and Child Health Index of Life with Disabilities Dutch version; PedsQL, Pediatric Quality of Life Inventory™.

*Significant at $p < 0.05$.

**FIGURE 1** Growth curve of the Caregiver Priorities and Child Health Index of Life with Disabilities Dutch version total scores in the Botox group

This supports the representativeness of the sample. The results reported here follow completely the pattern we hypothesized for four analyses and partially in the remaining three. These findings support the longitudinal validity of the CPCHILD-DV.

The first hypothesis stating that the intervention groups will show a significant larger mean change-score than the non-intervention group is confirmed by significant positive mean change-scores in the intervention group at 3 and at 6 months and no significant change-scores for the non-intervention group. The second hypothesis stating that the group with Botox intervention will have the highest CPCHILD-DV score at 3 months (because of the temporary effect of Botox) and the third hypothesis that the group with gastrostomy tube

intervention will have highest score at 6 months are also confirmed. The fourth hypothesis was about a positive mean change-score of at least the minimal clinically important difference in the intervention group. In the Botox group, this was confirmed by a mean change-score higher than the prespecified minimal clinically important difference of 5.8 points. This CPCHILD-DV mean change-score was higher than the mean change-score of the PedsQL that also confirms the fifth hypothesis for the Botox group.

In the gastrostomy group, the fourth and fifth hypotheses were not confirmed. The positive change-score did not reach the minimal clinically important difference. Due to the low number in the gastrostomy group, the results should be interpreted with caution.

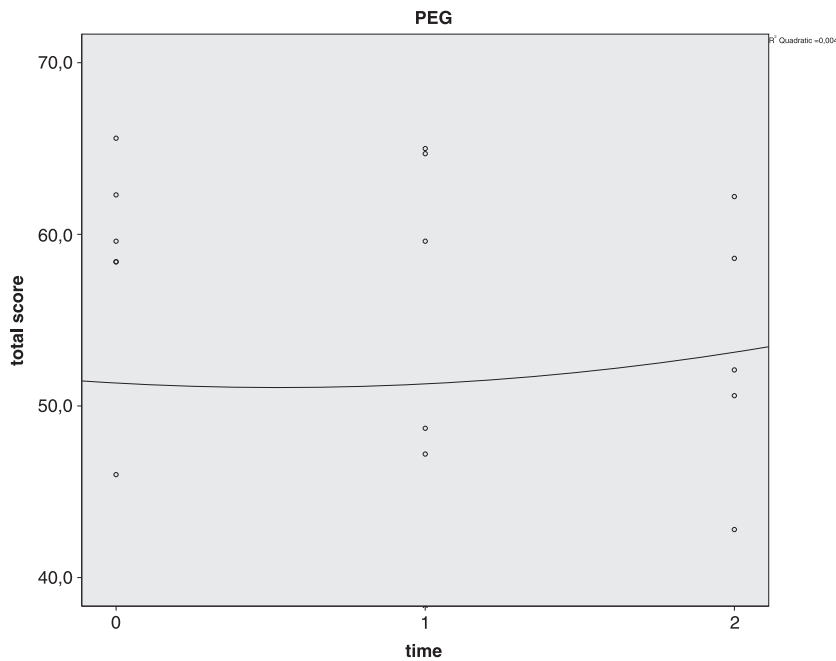


FIGURE 2 Growth curve of the Caregiver Priorities and Child Health Index of Life with Disabilities Dutch version total scores in the gastrostomy group

TABLE 3 Spearman's correlation of CPCHILD-DV and PedsQL with caregivers' perceived change in quality of life of child

Caregivers' perceived change in quality of life of child (n = 34)						
Quality of life	CPCHILD-DV	3 months	6 months	PedsQL	3 months	6 months
		rho	rho		rho	rho
Total score	Total score	0.49**	0.33	Total score	0.25	0.48*
Physical domain	Personal care	0.58**	0.23	Physical health summary score	0.03	-0.18
	Health	0.22	0.25		-0.06	0.16
	Positioning, transferring, and mobility	0.10	0.11		0.30	0.13
Psychological domain	Comfort and emotions	0.46**	0.35	Psychosocial health	0.33	0.32
Social domain	Communication and social interaction	-0.17	0.09	summary score	0.38*	0.30

Abbreviations: CPCHILD-DV, Caregiver Priorities and Child Health Index of Life with Disabilities Dutch version; PedsQL, Pediatric Quality of Life Inventory™.

*Correlation is significant at the 0.05 level (two-tailed).

**Correlation is significant at the 0.01 level (two-tailed).

Mahant, Friedman, Connolly, Goia, and Macarthur (2009) found a trend of increased health-related quality of life in children with CP after a gastrostomy tube placement, but no significant improvement after 6 and 12 months. Caregivers however generally felt that the intervention had a positive impact on their overall child's health. This was also found in the study of Sullivan et al. (2005). In our study, this is in accordance with the highest change-score on the domain level in the domain health in the gastrostomy group.

The sixth hypothesis stated that the CPCHILD-DV score will show a significant correlation with the scores of caregivers' perceived change in health-related quality of life of the child. The moderate positive correlations of the CPCHILD-DV with the caregivers' perceived change in the domain personal care, comfort and emotions

(predominantly items about pain or discomfort), and the total score are in accordance with the effects of Botox and confirm the sixth hypothesis. Because a positive correlation coefficient means that for a positive increase in one variable, there is also a positive increase in the second variable, it is explicable that the highest correlation coefficient is in the first 3 months, due to the effect of the Botox. The last hypothesis—that the CPCHILD-DV change-scores will show higher correlations with the questionnaire scores of caregivers' perceived change in health-related quality of life of the child than the generic instrument will show—is confirmed at the 3-month change-score (A–B) but not at the 6-month score (B–C). The many missing items in the PedsQL might indicate that the PedsQL is not well suited for nonambulatory children with severe disabilities. Huang, Wen,

Revicki, and Shenkman (2011) concluded that the PedsQL did not demonstrate valid psychometric properties in a population of children with severe disabilities. However, as was stated in Section 1, there is no other condition-specific valid instrument available for nonambulatory children with severe disabilities. One has to use a more generic health-related quality of life instrument that is not specifically designed for this target group.

This study would have been more robust if the sample size was larger, especially in the gastrostomy group and the control group. It proved to be difficult to find enough nonambulatory children with severe disabilities who were scheduled for one of the two interventions, although we extended the inclusion period for a year and increased the centres that participated in recruiting. Further studies concerning gastrostomy and other interventions are required to support the longitudinal validity of the CPCHILD-DV.

Comparing the results of this study with the longitudinal validation study of the original instrument, we can see similar results (Narayanan, Sponseller, Weir, Marks, & Newton, 2010). That study followed children for 6 months undergoing instrumental spinal fusion for their scoliosis and showed a mean significant change-score of 6.6 points. There were clinically important and significant improvements for the domains positioning/transfer/mobility, comfort/emotions, and overall health-related quality of life. The correlations between the changes in the domain scores and the external ratings were modest positive.

In conclusion, the results of this study indicate that the longitudinal validity of the CPCHILD-DV is statistically and clinically adequate. Therefore, the CPCHILD-DV can be used as an outcome measure in nonambulatory children with severe disabilities.

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CONFLICT OF INTERESTS

The authors report no conflict of interests.

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REFERENCES

- Bjornson, K., & McLaughlin, J. (2001). The measurement of health-related quality of life (HRQL) in children with cerebral palsy. *European Journal of Neurology*, 8, 183–193. <https://doi.org/10.1046/j.1468-1331.2001.00051.x>
- Carlson, S., Shields, N., Yong, K., Gilmore, R., Sakzewski, L., & Boyd, R. (2010). A systematic review of the psychometric properties of quality of life measures for school aged children with cerebral palsy. *BMC Pediatrics*, 10. <https://doi.org/10.1186/1471-2431-10-81>
- Gross Motor Function Classification System. (2015, december 3). Retrieved from CanChild: <https://www.canchild.ca>
- Huang, I., Wen, P., Revicki, D., & Shenkman, E. (2011). Quality of life measurement for children with life-threatening conditions: Limitations and a new framework. *Child Indicators Research*, 4, 145–160. <https://doi.org/10.1007/s12187-010-9079-x>
- International standard classification of education. (2012). Retrieved nov 11, 2016, From Unesco.org: <https://uis.unesco.org/en/topic/international-standard-classification-education-iscd>
- Mahant, S., Friedman, J., Connolly, B., Goia, C., & Macarthur, C. (2009). Tube feeding and quality of life in children with severe neurological impairment. *Archives of Disease in Childhood*, 94, 668–673. <https://doi.org/10.1136/adc.2008.149542>
- Narayanan, U., Fehlings, D., Weir, S., Knights, S., Kiran, S., & Campbell, K. (2006). Initial development and validation of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD). *Developmental Medicine and Child Neurology*, 48, 804–812. <https://doi.org/10.1017/S0012162206001745>
- Narayanan, U., Sponseller, P., Weir, S., Marks, M., & Newton, P. (2010). Sensitivity of the CPCHILD questionnaire to change following surgery for scoliosis in children with severe cerebral palsy. *Developmental Medicine and Child Neurology*, 45–51.
- Norman, G., Sloan, J., & Wywrich, K. (2003). Interpretation of changes in health-related quality of life: The remarkable universality of half a standard deviation. *Medical Care*, 41, 582–592. <https://doi.org/10.1097/01.MLR.0000062554.74615.4C>
- Reid, S., Carlin, J., & Reddihough, D. (2011). Using the Gross Motor Function Classification System to describe patterns of motor severity in cerebral palsy. *Developmental Medicine and Child Neurology*, 53, 1007–1012. <https://doi.org/10.1111/j.1469-8749.2011.04044.x>
- Schiariti, V., Fayed, N., Cieza, A., Klassen, A., & O'donnell, M. (2011). Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning. *Disability and Rehabilitation*, 33, 1330–1339. <https://doi.org/10.3109/09638288.2010.531371>
- Sullivan, P., Juszcak, E., Bachlet, A., Lambert, B., Vernon-Roberts, A., Grant, H., ... Thomas, A. (2005). Gastrostomy tube feeding in children with cerebral palsy: A prospective, longitudinal study. *Developmental Medicine and Child Neurology*, 47, 77–85. <https://doi.org/10.1017/S0012162205000162>
- Terwee, C., Dekker, F., Wiersinga, W., Prummel, M., & Bossuyt, P. (2003). On assessing responsiveness of health-related quality of life instruments: Guidelines for instrument evaluation. *Quality of Life Research*, 12, 349–362. <https://doi.org/10.1023/A:1023499322593>
- Varni, J., Seid, M., & Kurtin, P. (2001). PedsQL 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in

healthy and patient populations. *Medical Care*, 39, 800–812. <https://doi.org/10.1097/00005650-200108000-00006>

Zalmstra, T., Elema, A., Boonstra, A., Maathuis, K., Narayanan, U., Putten, A. v.d., ... Lindeboom, R. (2015). Validation of the Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) in a sample of Dutch non-ambulatory children with cerebral palsy. *Disability and Rehabilitation*, 37, 411–416. <https://doi.org/10.3109/09638288.2014.923524>

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