

## ORIGINAL ARTICLE

# The Danish child and parent Gait Outcomes Assessment List questionnaires were reliable and valid for cerebral palsy

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## Abstract

**Aim:** We investigated the reliability and validity of the Danish child and parent versions of the Gait Outcomes Assessment List (GOAL) questionnaires for ambulatory children with cerebral palsy (CP).

**Methods:** Translation and cultural adaptations were performed and content validity evaluated. Participants were enrolled between 2016 and 2018 from Aarhus University Hospital, Denmark. Children and parents completed the GOAL questionnaires twice for test-retest reliability. Discriminative validity was evaluated by comparing the child and parent GOAL scores between children with Gross Motor Function Classification System (GMFCS) levels I and II. The concurrent validity of the GOAL questionnaires were investigated by comparing them with Challenge-20, which assesses motor skills in children with CP.

**Results:** We studied 59 children (57% boys) with CP and GMFCS I-II at a mean age of 10.6 years. Test-retest intra-class correlations were excellent for the children (0.91, 95% confidence interval (CI) 0.83–0.96) and good for the parents (0.83, 95% CI 0.67–0.91). GOAL scores decreased with increasing GMFCS ( $p < 0.05$ ). Both versions correlated well. The mean children's scores were significantly (6.2/100) higher than the parents' ( $p < 0.001$ ). The GOAL scores correlated positively with Challenge-20.

**Conclusion:** The Danish GOAL child and parent questionnaires demonstrated good reliability and content and discriminative and concurrent validity.

## KEYWORDS

ambulatory children, cerebral palsy, gait outcomes, reliability, validity

## 1 | INTRODUCTION

Most children with cerebral palsy (CP) are ambulant<sup>1,2</sup> and the musculoskeletal impairments associated with CP affect their gait abilities.<sup>3</sup> That is why they are offered a multitude of interventions during their childhood.<sup>3</sup> These interventions target impairments,

such as spasticity, muscle weakness, contractures or lever arm dysfunction. They also improve their gait efficiency, physical activity and participation in life activities.<sup>3,4</sup> It has been recommended that children and their parents should identify and prioritise their intervention goals<sup>2</sup> and that treatment decisions should consider these individual goals and preferences.<sup>3,5-7</sup> Patient-reported

**Abbreviations:** CI, confidence intervals; CP, cerebral palsy; GMFCS, Gross Motor Function Classification System; GMFM-66, Gross Motor Function Measure; GOAL, Gait Outcome Assessment List; ICC, intra-class correlation coefficient.

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outcome measures could be used to drive treatment goals, if the content of the measures reflect the priorities and goals of the person with CP.<sup>6-8</sup> The World Health Organization has established an International Classification of Functioning, Disability and Health that can be used for ambulatory children with CP.<sup>9</sup> However, standardised patient-reported outcome measures, which clinicians can use to comprehensively assess important domains for these patients, have been lacking.

Various gross motor function and gait functional assessments have been used for CP, but these do not incorporate patient-reported priorities.<sup>10</sup> The Gait Outcomes Assessment List (GOAL) questionnaires were developed in 2014 to address this gap for ambulant children with CP, who function at Gross Motor Function Classification System (GMFCS) levels I-III.<sup>11-13</sup> The development of the separate child and parent GOAL versions included interviews with children with CP and their parents, to identify their priorities and goals. There was additional input from healthcare professionals from multiple disciplines.<sup>12,13</sup> The GOAL questionnaires can be self-reported by children with CP and/or by their parents.<sup>12</sup> A number of studies have validated the GOAL questionnaires to date and these showed that they were able to discriminate between GMFCS levels I-III.<sup>13,14</sup> Moderate positive correlations were found between the GOAL scores and the walking and activities lists in the Functional Mobility Scale and Functional Assessment Questionnaire.<sup>13</sup> A moderate negative correlation was found between the total GOAL scores and the gait profile score derived from the three-dimensional gait analysis.<sup>13</sup>

The test-retest reliability evaluation of the children's GOAL scores and the reliability among different age groups have not been reported. The GOAL questionnaires have not been compared with the 66-item Gross Motor Function Measure (GMFM-66) performance test, which is one of the most commonly used outcome measures used for this population.<sup>15,16</sup> Challenge-20 is an observational measure that was developed as an adjunct to the GMFM-66, to evaluate advanced gross motor performance in school-aged children with CP GMFCS I and II and this was also used in this study.<sup>17-20</sup>

The aim of this study was to translate the GOAL questionnaires into Danish and to adapt them to develop child and parent versions of the questionnaires. We wanted to evaluate their face validity and discriminative validity and test-retest reliability. In addition, we aimed to investigate the correlation between responses from the children and their parents and the concurrent validity of the GOAL questionnaires with the Challenge-20 measure.

## 2 | MATERIALS AND METHODS

### 2.1 | Study design

This was a prospective cross-sectional study that was conducted between 04 January 2016 and 31 October 2018 in the Department of Children's Orthopaedics, Aarhus University Hospital, Denmark.

### Key Notes

- We investigated the reliability and validity of the Danish child and parent versions of the Gait Outcomes Assessment List (GOAL) questionnaires for ambulatory children with cerebral palsy.
- The children, parents and professionals found the GOAL items relevant and the test-retest intra-class correlations were excellent for the children, at a mean age of 10.6 years, and good for parents.
- Both questionnaires demonstrated good reliability and content and discriminative and concurrent validity.

- A. activities of daily living and independence (9 items)
- B. gait function and mobility (10 items)
- C. pain, discomfort, and fatigue (7 items)
- D. physical activities, sports, and recreation (8 items)
- E. gait pattern and appearance (6 items)
- F. use of braces and mobility aids (3 items)
- G. body image and self-esteem (6 items)

FIGURE 1 Gait Outcome Assessment List domains and items.

### 2.2 | Outcome measures

The GOAL questionnaires are available in two versions: one self-report format for children (GOAL-Child) and one for parents (GOAL-Parent). Both GOAL versions consist of 49 items grouped into seven domains or subscales. Domain A comprises nine items covering activities of daily living and independence. B provides 10 items on gait function and mobility. C is seven items covering pain, discomfort and fatigue. D refers to eight items on physical activities, sport, and recreation. E contains six items on gait pattern and appearance and F provides three items on the use of braces and mobility aids. G comprises six items on body image and self-esteem (Figure 1). The GOAL-Child and GOAL-Parent questionnaires provide the same questions, but address the children and parents, respectively.

The GOAL scoring procedure was performed according to the guide provided.<sup>13</sup> As well as rating the performance of each item, the respondents can rate whether improving that item is an important goal. This identifies the individual child's or parent's goals, which can be used to guide decision-making, but does not contribute to the score. The standardised domain and total GOAL scores range from zero for worst to 100 for best.<sup>13</sup>

The GMFM-66 is one of the most commonly used outcome measures for motor skills for children with CP. It has been shown to have a ceiling effect when used in children with GMFCS level I who are over 5 years of age.<sup>15,16</sup>

The Challenge-20 measure<sup>17</sup> was developed as an adjunct to the GMFM-66 for school-aged children from 5 to 18 years with CP who function at GMFCS I and II.<sup>15-17</sup> It is an observational assessment used by certified physiotherapists to measure performance ability related to a child's coordination, accuracy and speed during advanced motor skills.<sup>17-20</sup> Challenge-20 comprises 20 items divided into three categories. The balance and coordination category comprises seven items. Walk, run and jump contain 10 items and dual tasks contain three items. It has been shown to be valid and reliable in its original English version,<sup>17</sup> its translated Danish version<sup>18</sup> and its Brazilian-Portuguese version.<sup>19</sup> We used the Danish version of the Challenge-20 version in this study.<sup>18</sup> Challenge-20 scores 0-4 for each item and three of the 20 items evaluate the right and left sides separately, which can add an extra 12 points to the score.

This means that the total score ranges from zero for worst to 92 for best.<sup>17</sup> The best Challenge-20 total score of three trials was used.

### 2.3 | Procedures

The two GOAL questionnaires were translated into Danish. The original English questionnaires, versions 4.3, were accessed with permission from the developer (Unni Narayanan, The Hospital for Sick Children in Toronto and Toronto University, Canada).<sup>12,13</sup> The translations were performed following Wild et al.<sup>21</sup> Two native Danish-speaking people independently carried out the forward translations: a paediatric physiotherapist with fluent English and knowledge of the construct to be measured and a professional linguistic translator. The preliminary Danish versions of the GOAL questionnaires were agreed by a group that comprised the principal investigator and paediatric physiotherapist and two paediatric orthopaedic surgeons. A second professional linguistic translator, who was blinded to the original GOAL versions, performed backward translations of the final Danish GOAL questionnaires into English. The original GOAL developer approved the back-translated versions.

### 2.4 | Participants and setting

Children aged 5-18 years with a confirmed diagnosis of CP, classified as GMFCS level I or II, were eligible to take part if they were able to understand the Danish GOAL-Child questionnaire. They were recruited from the outpatient clinic with their parents. Children were excluded if they had received an intervention within the previous 3 months, namely surgery, a botulinum neurotoxin A injection or being put in a cast.

Families decided whether the child or parents or both completed the GOAL questionnaires. This was carried out during appointments with the child and their parents, using a paper or Internet-based version. They were then completed again 7-14 days later, at home. Parents were allowed to read the questions if the children needed help, but were told not to interpret the questions.

A research assistant entered the raw GOAL data into a 2015 Excel spreadsheet (Microsoft Corp, Washington, USA), provided by the GOAL developers, which automatically calculated the scores.<sup>13</sup>

### 2.5 | Face and content validity

Face validity assessment was carried out. The children and parents were asked whether the wording of the questionnaires, and the meaning of the items and domains, were clear and easy to understand. They were also asked about their overall impressions and the relevance of the items and domains for evaluating gait-related function. Two paediatric physiotherapists and two paediatric orthopaedic surgeons also assessed the relevance, meaning and linguistic clarity of the items and domains.

### 2.6 | Test-retest reliability

Participants who agreed to complete the GOAL questionnaire twice, in the clinic and at home, were included in the reliability testing process. The first GOAL questionnaires were completed during an outpatient appointment. They were then completed at home 7-14 days later, as recommended for the reliability testing of longer questionnaires.<sup>22</sup> Parents were asked to report any change in their child's health status between the questionnaires. The participants were blinded to their scores on the initial questionnaire. We hypothesised that the child and parent versions of the Danish GOAL questionnaires would be reliable, with good intra-class correlations (ICC) of between 0.75 and 0.90.<sup>23</sup> The number of children and parents who took part in this process was based on the Consensus-based Standards for the Selection of Health Measurement Instruments recommendations for a good sample size of at least 50-99.<sup>24</sup>

### 2.7 | Discriminative validity

To assess the discriminative validity of the GOAL questionnaires, we compared the child and parental scores between children functioning at GMFCS levels I and II and hypothesised that these would be higher for level I.

### 2.8 | Correlation between GOAL child and parent scores

The child and parent baseline scores were used to compare the domain and total GOAL scores. We calculated any systematic differences between the two set of responses and expected to see a positive correlation between the two.<sup>13</sup>

## 2.9 | Concurrent validity of the GOAL versions and Challenge-20

Children who had the Challenge-20 assessment on the same day that they completed their first GOAL questionnaire were included in the concurrent validity evaluation. The total child and parent GOAL scores were correlated, with the best score during the child's baseline Challenge-20 being used. Correlations between the Challenge-20 measures and GOAL domains A, B and D, covering daily living activities and independence, gait function and mobility and physical activities, sports and recreation, were also carried out. We expected these correlations to be the strongest.

### 2.10 | Statistical analysis

Normality assumptions were investigated before the statistical analysis. Test-retest reliability was assessed as ICCs and shown as 95% confidence intervals (95% CIs) and standard errors of measurement.<sup>23</sup> The ICC was poor if  $<0.5$ , moderate if  $0.5-0.75$ , good if  $0.75-0.9$ , and excellent if  $>0.9$ .<sup>23</sup> The agreement between assessments were evaluated using Bland-Altman plots and are shown as means, 95% CIs, and 95% limits of agreement.<sup>25,26</sup> The discriminative validity of the GOAL questionnaires were evaluated using the Wilcoxon rank sum test and the total GOAL scores for GMFCS levels I and II were compared. A ceiling effect was considered present if at least 15% of the respondents had a GOAL score of  $\geq 95$ .

We compared the correlations between the GOAL-Child and GOAL-Parent scores by analysing the total and domain scores from baseline, using a paired t-test with mean standard deviations and differences and visualised them using a Bland-Altman plot. Concurrent validity between the total GOAL scores at baseline and Challenge-20 were assessed using Spearman rho and sub-analyses of the correlation between the respective GOAL domain A, B and D scores and Challenge-20. These were reported with  $r_s$ , 95% CI and  $p$  values.<sup>27</sup> Spearman rho was interpreted as good if  $>0.70$ .<sup>28</sup> Significance was defined as  $p < 0.05$  and the statistical analyses were performed using Stata 16 software (StataCorp, Texas, USA).

### 2.11 | Ethics

Information about the study was provided. Parents and children aged 18 years provided written consent to participate and all the younger children provided oral assent. The paper questionnaires were stored in accordance with data protection law. Online data were collected and managed using Research Electronic Data Capture tools (Vanderbilt University, Tennessee, USA) hosted at Aarhus University, Denmark. This study was approved by the Danish Data Protection Agency, Central Region Denmark (number 615216) and the local ethics committee was notified.

## 3 | RESULTS

### 3.1 | Descriptive results

We identified 111 children with ambulant CP and 59 (58%) were enrolled. Nine were excluded as they functioned at GMFCS III, and 43 declined to participate. The mean age of the cohort was  $10.6 \pm 3.5$  years (range 5-18) and 57% were boys. They followed a normal distribution when examined by a QQ plot.

The summarised descriptive statistics are presented in Table 1, including the number who responded, as there were missing responses in some domains.

The investigation of the total GOAL scores and domain scores distribution showed a non-normal distribution. The reliability estimation and discriminative assessment revealed that the data were normally distributed.

### 3.2 | Translation

A number of linguistic revisions were performed to the GOAL questionnaires to conform with the semantic and cultural requirements of Danish patients. Changes were made to item 10 in Domain B about walking for more than 250m and item 31 in Domain D about participating in sports that required running. These reflected comparisons with familiar sports in Danish schools. We did not receive any additional suggestions for changes to items or domains.

### 3.3 | Face and content validity of the GOAL questionnaires

All GOAL domains and items were considered acceptable and relevant to most children, parents and professionals. Participants reported that they found a few items that were not currently relevant to their child. These included the Domain B items related to physical activities, sports and recreation, gliding sports, such as skating, rollerblading, skiing and skateboarding or snowboarding, and sports that require jumping, such as soccer, basketball and volleyball. Some items in Domain F, namely using braces and mobility aids, were not relevant to all children. Two families commented that, although they found that not all items were equally relevant for their child, they could be relevant for other ambulatory children with CP in general.

### 3.4 | Reliability of the GOAL questionnaires

The GOAL questionnaires were completed a second time by 69% of the children and 70% of the parents who completed the initial questionnaire at baseline. The mean time between the two administrations for test-retest reliability was 11.3 days. The test-retest reliability was excellent and good for the GOAL-Child and GOAL-Parents' total GOAL scores, respectively (Table 2; Figure 2).

TABLE 1 Descriptive statistics of GOAL total scores and domain scores by GMFCS level.

	GMFCS level I			GMFCS level II			Comparison
	n = 34	Median	Range	n = 25	Median	Range	p-Value
GOAL total score							
Child questionnaire	25	84.2	65.4–99.5	23	79.2	27.0–93.5	0.006
Parent questionnaire	32	79.3	51.9–95.4	25	74.4	42.0–89.2	0.072
Domain A							
Child questionnaire	25	97.5	86.4–100	22	90.1	72.8–100	0.025
Parent questionnaire	32	96.3	63.5–100	24	88.9	47.2–100	0.056
Domain B							
Child questionnaire	25	93.0	72.5–100	22	81.5	62.0–100	0.038
Parent questionnaire	32	86.5	65.6–100	24	81.0	50.0–100	0.052
Domain C							
Child questionnaire	25	81.0	45.2–100	21	83.3	33.3–100	0.877
Parent questionnaire	31	81.0	38.1–100	23	81.0	31.0–100	0.534
Domain D							
Child questionnaire	25	80.0	33.3–100	23	61.9	16.2–95.8	0.007
Parent questionnaire	31	58.3	38.9–100	25	52.8	25.0–90.0	0.242
Domain E							
Child questionnaire	25	86.1	44.4–100	23	75.0	30.6–100	0.009
Parent questionnaire	32	83.3	19.4–100	25	66.7	13.9–94.4	0.038
Domain F							
Child questionnaire	9	75.0	25–100	15	50.0	25.0–100	0.180
Parent questionnaire	10	75.0	0–100	15	50.0	25.0–100	0.085
Domain G							
Child questionnaire	23	70.8	20.8–100	22	62.5	33.3–87.5	0.098
Parent questionnaire	32	54.2	12.5–100	25	50.0	29.2–100	0.539

Note: Numbers (n), medians and ranges for total scores and domain scores. Wilcoxon rank sum test: comparison between GMFCS level I and GMFCS level II, significance ( $p < 0.05$ ).

TABLE 2 Test-retest reliability and correlation of the GOAL-Child and GOAL-Parent, by age groups.

	Child				Parent			
	n	ICC (95% CI)	LoA (95%)	SEM	n	ICC (95% CI)	LoA (95%)	SEM
GOAL total score	33	0.91 (0.83; 0.96)	-10.6; 14.4	4.02	40	0.83 (0.67; 0.91)	-19.1; 10.6	4.79
5–8 years	10	0.97 (0.90; 0.99)	-6.6; 9.9	3.21	14	0.83 (0.55; 0.94)	-19.1; 4.9	5.64
9–12 years	14	0.57 (0.10; 0.84)	-10.6; 14.4	4.89	16	0.81 (0.55; 0.93)	-13.1; 10.6	4.12
13–18 years	9	0.95 (0.79; 0.99)	-8.5; 7.1	3.26	10	0.81 (0.34; 0.95)	-12.7; 5.8	4.47

Note: Intra-class correlation coefficient.

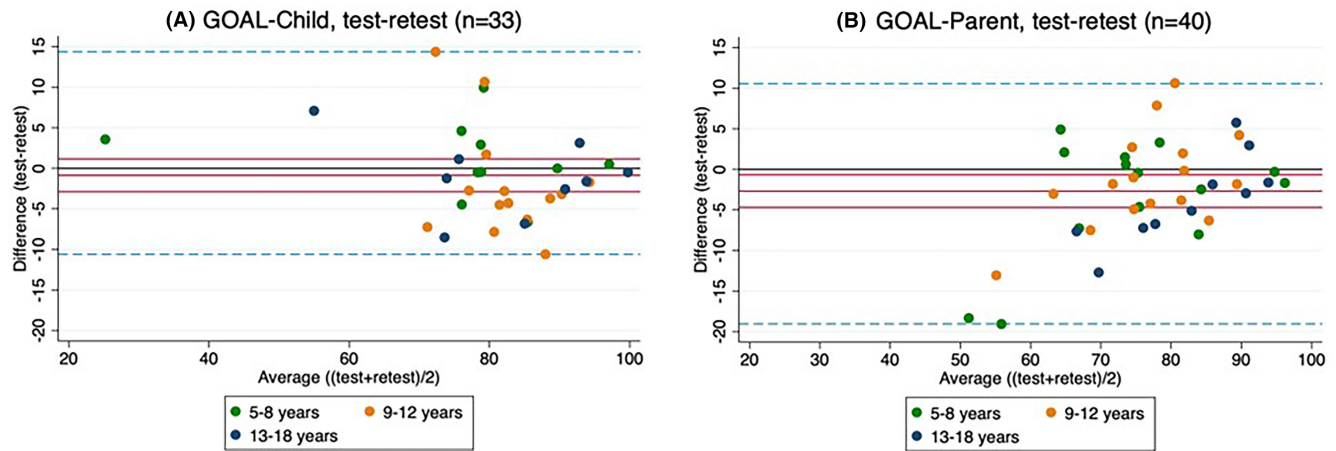
Abbreviations: 95% CI, confidence interval, LoA, limits of agreement, SEM, standard error of measurement.

Test-retest reliability, based on the GOAL-Child total scores by age group, was excellent for children aged 5–8 and 13–18 year, and moderate for those aged 9–12 years (Table 2).

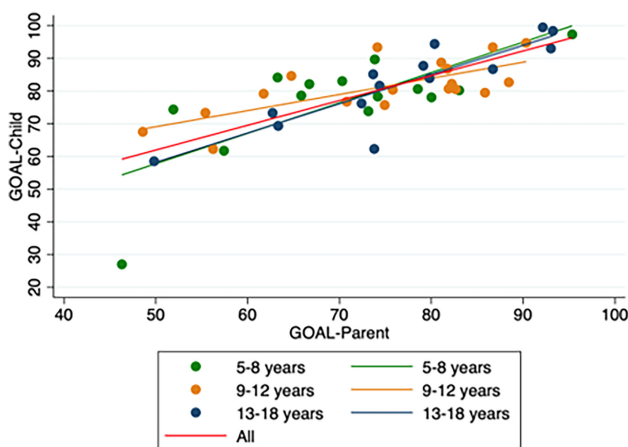
### 3.4.1 | Discriminative validity of the GOAL questionnaires

As hypothesised, the total GOAL scores, and some domain scores, were higher in children with GMFCS level I than level II (Table 1).

The children's scores were significantly different between the GMFCS levels for the total GOAL score ( $p < 0.01$ ). This was also the case for domain A covering activities of daily living and independence ( $p = 0.03$ ), B for gait function and mobility ( $p = 0.04$ ), D for physical activities, sports and recreation ( $p < 0.01$ ) and E for gait pattern and appearance ( $p < 0.01$ ) (Table 1). The parents' total GOAL score was higher if their children had GMFCS level I than level II, but this difference did not reach statistical significance ( $p = 0.07$ ). The differences were significant for domain B for gait function and mobility ( $p = 0.05$ ) and E for gait pattern and



**FIGURE 2** Test-retest of GOAL-Child and GOAL-Parent. GOAL, Gait Outcome Assessment List. Agreement illustrated by Bland-Altman plot with comparison between different assessments total scores. The dots colours represent the three age groups. The difference between two assessment total scores on the vertical axis are plotted against the average of the two assessment total scores on the horizontal axis. (A) Test-retest from GOAL-Children. The middle horizontal red line reflects the mean difference  $-0.87\%$  and 95% confidence interval (CI) red lines ( $-2.89$ ;  $1.16$ ) and the blue-dashed lines the upper and the lower line the Limits of Agreement (LoA;  $-10.60$ ;  $14.36$ ). (B) Test-retest from GOAL-Parent's GOAL. The middle horizontal red line reflects the mean difference  $-2.67$  and 95% CI ( $-4.69$ ;  $-0.66$ ) and the blue-dashed lines upper and the lower line the LoA ( $-19.05$ ;  $10.55$ ).



**FIGURE 3** Correlation: plots of scores from GOAL-Child and GOAL-Parent. GOAL, Gait Outcome Assessment List. X, Y plots, comparison of GOAL-Child and GOAL-Parent, baseline same day.

appearance ( $p=0.04$ ) (Table 1). The responses from the parents and children on domain C, for pain, discomfort and fatigue, were similar between the GMFCS levels.

### 3.5 | Correlation between child and parent questionnaire scores

The initial GOAL questionnaire responses from the 46 children were compared with their respective parents' responses (Figure 3). The GOAL-Child scores ranged from 27.0 to 99.5 and the GOAL-Parent scores ranged from 42.0 to 95.4. Despite these wide range distributions, the QQ plots were left-skewed and showed a non-normal

distribution. As a result, we have reported total scores as median and range scores (Table 1). The GOAL-Child total scores had a good positive correlation with their GOAL-Parent total scores, according to Spearman's rho ( $0.72$ , 95% CI  $0.56-0.89$ ,  $p \leq 0.001$ ). However, the children's total scores were an average of 6.2/100 points (95% CI 3.6-8.8,  $p < 0.001$ ) higher than their parents' scores (Table 3). This was significant and was true for all three age groups. In addition, the children reported significantly higher scores than their parents for all domains, except F for the use of braces and mobility aids. The children's scores were higher than their parents' scores in five of the seven domains if they had GMFCS I and six of the seven domains if they had GMFCS II (Table 1). There was no ceiling effect for the GOAL-Child responses or the GOAL-Parent responses for either GMFCS level I or II.

### 3.6 | Concurrent validity of the GOAL questionnaires and Challenge-20

The total baseline scores for the GOAL-Child and GOAL-Parent questionnaires were correlated to the Challenge-20 score for the 41 children who completed that measure. The GOAL-Child total score had a weak positive correlation with the Challenge-20 score, according to Spearman's rho ( $0.30$ , 95% CI  $-0.01$  to  $0.56$ ,  $p=0.06$ ). The GOAL-Parent total score had a weak positive correlation with the Challenge-20 score, according to Spearman's rho ( $0.34$ , 95% CI  $0.04-0.59$ ,  $p=0.03$ ). Both versions had a positive correlation with the Challenge-20 questionnaire domain scores for A for activities of daily living and independence, B for gait function and mobility and D for physical activities, sports and recreation. See Appendix S1 for the detailed results.

**TABLE 3** Correlation of GOAL-Child and GOAL-Parent scores, by means and mean differences.

	n	Child	Parent	Mean difference (child-parent)	
		Mean (SD)	Mean (SD)	Mean (95% CI)	p-Value
GOAL total	46	80.0 (12.6)	73.8 (12.6)	6.2 (3.6–8.8)	<0.001
Age groups					
5–8 years	14	76.4 (16.3)	70.0 (12.9)	6.4 (–0.1–12.8)	0.052
9–12 years	18	81.2 (8.6)	74.6 (12.5)	6.6 (2.3–10.9)	0.005
13–18 years	14	82.2 (12.8)	76.8 (12.5)	5.4 (1.8–9.0)	0.007
Domains					
Domain A	45	92.8 (7.5)	88.4 (11.6)	4.4 (1.6–7.2)	0.003
Domain B	45	87.5 (11.0)	83.9 (11.7)	3.6 (1.3–6.0)	0.003
Domain C	43	81.6 (14.6)	77.5 (17.7)	4.1 (0.0–8.2)	0.050
Domain D	46	68.5 (19.9)	56.7 (16.4)	11.7 (6.9–16.5)	<0.001
Domain E	46	75.9 (19.7)	67.8 (22.8)	8.1 (3.5–12.7)	<0.001
Domain F	22	68.2 (24.6)	55.1 (24.6)	13.1 (–2.3–28.4)	0.091
Domain G	43	65.2 (18.7)	58.2 (20.5)	6.9 (0.9–13.0)	0.026

Note: p value; T-test, significance ( $p < 0.05$ ).

Abbreviations: 95% CI, confidence interval; SD, standard deviation.

## 4 | DISCUSSION

The GOAL questionnaires have been specifically developed to provide a more meaningful patient-reported outcome measure for ambulatory children with CP. The child and parent versions explicitly capture the goals and priorities of this population, which other patient-reported outcome measures do not. We successfully translated the GOAL questionnaires into Danish and studied the psychometric properties of the GOAL-Child and GOAL-Parent versions in a Danish context. Children, parents, and professionals reported that the GOAL questionnaires were understandable, culturally appropriate and relevant. It is important that they provided evidence of strong face and content validity.

The GOAL-Child answers were reliable, with excellent test–retest reliability (ICC 0.91), which had not been previously reported. The GOAL-Parent questionnaire had a good test–retest reliability (ICC 0.82), as previously reported. The GOAL questionnaire's reliability was also confirmed in the sub-analysis evaluation of the GOAL-Child and GOAL-Parent questionnaires in different age groups. The reliability of the children's reports remained excellent for those aged 5–8 and 13–18 years and moderate for those aged 9–12 years. The reliability of the GOAL-Parent questionnaire was good for all the children's age groups.

The total GOAL score was significantly higher in children with GMFCS I than II and revealed good discriminative validity between these two grades, as hypothesised (Table 2). Two previous studies on the original GOAL questionnaires also supported their discriminatory validity.<sup>13,29</sup>

As hypothesised, we found that GOAL-Parent questionnaire scores were consistently lower than the GOAL-Child questionnaire scores (Figure 3; Table 3), in line with a validation study by Narayanan et al. and Bonfert et al. reported similar results for their German study.<sup>14,29</sup> Our results confirm that children with CP see

themselves as less impaired or limited in their gait, daily function and activities than their parents do. Recognising the different perspectives of children and their parents is important. In this study, children and parents reported particularly high ratings for the domains for physical activities, sports and recreation and body image and self-esteem. Using the results of the GOAL questionnaires completed by both parents, and, where possible, children, will reveal different perspectives and priorities. This provides an opportunity to discuss these differences and use this information to guide decision-making. However, child and parent versions must be validated before they are applied in daily clinical practice and used to set goals and evaluate interventions. Boyer et al. showed that the GOAL questionnaires were a valid tool that could help to identify the main goals and the importance of items that needed to be improved by GMFCS levels.<sup>30</sup> This might be crucial in shared decision-making when it comes to capturing the child's aims and perspectives across all International Classification of Functioning domains when prioritising intervention goals for their rehabilitation. If a child sets a goal to improve their function in one item, this item on its own might be important. Therefore, a better score not only means an improvement but also means that a child has achieved more independence in this activity.

Two previous GOAL studies assessed concurrent validity by comparing the GOAL questionnaires with the Functional Mobility Scale and Functional Assessment Questionnaire assessments of motor function. These showed moderate correlations, because they assessed similar constructs.<sup>13,29</sup> In addition, the GOAL questionnaires have been evaluated using the Gait Profile Score. This is a single index score of how the child's gait deviates from normal and is derived from three-dimensional gait analysis.<sup>13</sup> As expected, the results showed a moderate negative correlation and a higher total GOAL score was associated with a lower, namely better, Gait Profile Score.<sup>13</sup> The authors highlighted how unique the GOAL

questionnaires were, as they provided meaningful information about the child's function across multiple dimensions. These included environmental and personal factors that contributed to function, which are not included in the other outcome measures used for this population.<sup>13</sup> Our results underscore the importance of having responses to both the children's and parents' GOAL questionnaires, as they rated the items and domains differently.

We chose to compare the GOAL questionnaires with the Challenge-20 measure, which is based on a physiotherapist's standardised observations of the child's capacity to perform higher functional skills. Finding a positive correlation would provide some reassurance that the responses to the GOAL questionnaires by children and parents were a valid assessment of their gait and motor function. Our study showed that the total GOAL scores showed a modest positive correlation with Challenge-20. This is not a patient or parent reported outcome measure and provides different information to the GOAL questionnaires. The Challenge-20 measure quantifies motor function. In contrast, the GOAL questionnaires capture the real-world implications of those functions, based on the lived experience of the children, the parents' observations and the goals of the respondents. The GOAL questionnaires are multidimensional, as they include International Classification of Function domains of importance related to gait and motor functions that are not captured by Challenge-20. The GOAL questionnaires ask the respondent to report whether improving a specific item is an important goal for them. This unique feature allows the GOAL questionnaires to capture the children's and parents' goals while also generating an outcome score. Using both the Challenge-20 and GOAL questionnaires together might provide complementary and important information on children with CP.

#### 4.1 | Limitations

The discriminative validity evaluation was based on 59 children, which followed the recommendations for a good sample size. However, the small numbers of children in each age group was a limitation when it came to reaching conclusions about correlations between children of different ages and their parents.<sup>24</sup> The retest responses were only obtained from 33/40 of the participants, because some families did not complete the questionnaire again within 14 days.

Our study was limited to children who functioned at GMFCS levels I and II, whereas other studies have appropriately included children at GMFCS level III. We excluded children at GMFCS level III, because they only represented only 8% of our outpatient cohort and it was felt that the small GMFCS III sample would limit the robustness of the results in that group. Our study revealed that the distribution of the total GOAL scores was not normal, with respective medians of 84 and 79 for the children and parents in the GMFCS I group and 79 and 74 in the GMFCS II group. No ceiling effect was found for either questionnaire at either GMFCS level. However, these scores were at the higher end of the scale, because we did not include children at GMFCS level III. If we had included these children, who had more complex gait and motor

function impairments, we would have expected a wider distribution of scores, as reported in other published studies. We intend to evaluate the GOAL questionnaires in children at GMFCS level III in the future. We did not evaluate the responsiveness or sensitivity of the GOAL questionnaires to detect clinically important changes after interventions. These should be assessed before widespread implementation of the GOAL questionnaires as outcome measures.

## 5 | CONCLUSION

The GOAL questionnaires were valid after they were translated into Danish for ambulant children with CP and GMFCS levels I and II. They provided reliable responses for both children and parents. The parents' GOAL responses correlated well with their children's, but they consistently rated their children lower than the children rated themselves. The perspectives of children and parents can differ, and both should be measured whenever possible to capture these. The GOAL questionnaires were positively correlated with the Challenge-20 measure and this provided evidence of concurrent validity.

#### AUTHOR CONTRIBUTIONS

**Kirsten Nordbye-Nielsen:** Conceptualization; data curation; formal analysis; funding acquisition; investigation; methodology; project administration; writing – original draft; writing – review and editing. **Thomas Maribo:** Conceptualization; methodology; writing – original draft; writing – review and editing. **Ole Rahbek:** Conceptualization; methodology; writing – original draft; writing – review and editing. **Unni Narayanan:** Conceptualization; methodology; writing – original draft; writing – review and editing. **Bjarne Møller-Madsen:** Conceptualization; methodology; writing – original draft; writing – review and editing.

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#### CONFLICT OF INTEREST STATEMENT

Unni Narayanan was the lead developer of the original English version of the GOAL questionnaires but does not benefit financially from their use. The other authors have no conflicts of interest to declare.

#### DATA AVAILABILITY STATEMENT

The Danish GOAL questionnaires are available from the corresponding author.



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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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