Participation of children and youth with acquired brain injury

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Chapter 5
Psychometric evaluation of the Dutch language version of the Child and Family Follow-up Survey (CFFS)

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ABSTRACT

Aim The Child and Family Follow-up Survey is developed to monitor long term outcome of children and youth with acquired brain injury (ABI). The aim of the present study was to translate and adapt it into the Dutch language and to evaluate its reliability and validity.

Methods The CFFS includes the Child and Adolescent Scale of Participation (CASP), the Child and Adolescent Factors Inventory (CAFI), and the Child and Adolescent Scale of Environment (CASE). The CFFS was translated into Dutch following international guidelines and adapted. The internal consistency, validity and test-retest reliability were examined among 2 groups of patients (n=140 and n=27) in the age of 5-22 years with ABI and their parents.

Results The translation and adaptation resulted in the CFFS- DLV, Dutch Language Version. The CASP-DLV, CAFI-DLV and CASE-DLV had a good internal consistency, with Cronbach's alpha being 0.95, 0.89 and 0.83, respectively. There were statistically significant correlations among the three CFFS subscale scores. These scores were also significantly correlated with the total scores of the Paediatric Quality of Life Inventory (PedsQL, parent) and the Paediatric Stroke Outcome Measure (PSOM), but not with the domain scores of the Children's Assessment of Participation and Enjoyment (CAPE). The test-retest reliability was good to moderate, with the intra-class correlation coefficients being 0.90 for the CASP-DLV, 0.95 for the CAFI-DLV and 0.68 for the CASE-DLV.

Conclusion The CFFS-DLV, as translation and adaptation of the CFFS into Dutch, proved to be a promising instrument to measure long term outcome of children and youth with ABI. Further research is needed to examine its responsiveness to change and potential in other patient groups.

INTRODUCTION

Acquired brain injury (ABI) in children, adolescents and young adults (-24 years) may result from events with an external cause (traumatic brain injury, TBI) or internal cause (non-traumatic brain injury, NTBI) such as a brain tumour, stroke or infections such as meningitis or encephalitis.[1] The estimated yearly incidence rates in the Netherlands are 585/100 000 and 190/100 000, respectively for TBI and NTBI, with about 15% classified as moderate or severe.[2]

It is generally acknowledged that ABI in children and youth may have a considerable impact on their functioning and quality of life.[3,4,5] Participation, i.e. the nature and extent of a person's involvement in meaningful life situations at home, school, work and community life[6,7] is an important aspect of functioning. However, studies on the nature, incidence and specific patterns of participation problems of children and adolescents with ABI are relatively scarce. The available studies mainly focus on traumatic brain injury (TBI) and in general conclude on the increased occurrence of participation problems in comparison with healthy peers.[8-14]

In the literature, a range of very different instruments is used with respect to participation in children and youth with ABI as outcome measure. Specific and validated measures to assess the extent of ability and disability on the level of activities and participation among children and youth with ABI are needed for clinical care and research, to provide information that will assist decisions about intervention needs, potential intervention effects, and policies that address participation.[15]

The Child and Family Follow-up Survey (CFFS) is a relatively recently developed set of measures to assess long-term outcome regarding young people with ABI.[15-17] It includes the Child and Adolescent Scale of Participation (CASP), the Child and Adolescent Factors Inventory (CAFI), and the Child and Adolescent Scale of Environment (CASE) and is advocated for use as outcome measure in paediatric traumatic brain injury research.[18,19]

So far, in the Netherlands no ABI-specific instrument to monitor outcome on the level of activities and participation, applicable in clinical care and research, is available. Therefore, the aim of this study was (1) to translate and adapt the original English version of the CFFS into a Dutch language version and (2) to evaluate its psychometric qualities in children and youth with ABI in the Netherlands.

METHODS

1. Translation and cross-cultural adaptation of the CFFS

The CFFS

The CFFS[11,16] was developed for young people in the age group 4-21 years with ABI and consists of 5 sections: general information about actual functioning of the young one (section 1), the Child and Adolescent Scale of Participation (CASP) (2), The Child and Adolescent Factors Inventory (CAFI) (3A) and the Child and Adolescent Scale of Environment (CASE) (3B), actual child's needs and support (4A) and the family needs and support (4B), as well as suggestions to improve healthcare policy for youth with ABI and their families (5). The CAFI and the CASE are both included in the same section of the CFFS entitled "Problems experienced in daily life". The CASP, CAFI and CASE are quantitative measures and subject to this psychometric evaluation.

The CASP measures young people's extent of participation and restrictions in home, school and community life situations and activities compared to same-age peers as reported by a parent or caregiver. The CASP contains 20 items divided into four clusters: (1) Home Participation, (2) School Participation, (3) Community Participation and (4) Home and Community Living Activities. The items are rated on a 4-point scale (4=Age expected, 3=Somewhat limited, 2=Very limited, 1=Unable). In addition, an item can be rated as 'not applicable'. CASP summary scores (total and subsection) can be transformed to a 100-point scale by summing the scores from each applicable item, dividing this number by the maximum possible score (variable due to the number of applicable items) and multiplying this by 100. For the present study, the 'Not applicable' response options in the CASP were excluded from the analyses (if patients scored 'Not applicable' this item was not taken into account in the scoring).

The CAFI consists of 15 items focused on health-related problems with cognitive, psychological, physical and sensory functions as a result of the ABI-diagnosis. Each item or problem is rated on a 3-point scale: no problem (1), little problem (2), and big problem (3). CAFI summary scores (total and composite domain) can be calculated by summing the scores of all items, dividing this number by the maximum possible score, and multiplying this by 100. The scores, transformed to a 100-point scale, range from 33 to 100.

The CASE consists of 18 items related to physical, social and attitudinal environmental problems that children and youth may experience at home, school or in the community. Each item or problem is rated on a 3-point scale: No problem (1), little problem (2), big problem (3) or 'Not applicable'. CASE summary scores can be calculated by summing the scores of all items, dividing this sum by the maximum possible score, and multiplying it by 100. The score ranges from 0 to 100. For the present study, the 'Not applicable' response

options in the CASE were counted as 'no problem'. For the CASP a higher score indicates a better level of functioning, whereas for the CAFI and CASE a lower score indicates better levels of functioning.

Its reliability and validity have been established,[20] the CFFS has been translated into 3 other languages: Hebrew, Arabic and traditional Chinese. The CASP was translated in Spanish, French and German as well.[20]

Translation and adaptation of the CFFS

The aim of a linguistic validation is to produce a translated version in a foreign language, which is conceptually equivalent to the original version, as well as clear and easy to understand. The translated instrument should be understood by most respondents in a selected population and should maintain a reading and comprehension level that will be accessible by most respondents, even of a low education level. This aim was achieved by following international guidelines for cross-cultural translation and adaptation,[21,22] which distinguishes 4 steps.

In step 1 a forward translation of the English version of the CFFS into a Dutch version was independently made by two Dutch health care professionals (AdK=Arend de Kloet, CC=Coriene Catsman-Berrevoets). Both of them have Dutch as their mother tongue and are fluent in English, one of them with expertise on the construct under study. The two translations were compared, discrepancies resolved and synthesized into one Dutch provisional version (step 2). Then a professional, independent and bilingual translator (HM=Hanneke Meulenbroek) and a Dutch health care professional with English as mother tongue (FvM=Frederike van Markus-Doornbosch) made a back translation of the provisional Dutch version into the original English language (step 3). In step 4 an expert panel, consisting of the 4 translators, discussed the differences between the back translations and the original English version and checked whether the items had maintained their intended meaning.

2. Validation of the CFFS-DLV

Study design

The validation part of the present study had a cross-sectional design and was conducted in 2011 and 2012. It was approved by the Medical Ethics Committee of the Erasmus University Medical Centre in Rotterdam (MEC 2009-440).

Patients

For the present study recruitment was done among 2 different groups of patients with ABI and their parents (Cohorts 1 and 2). Cohort 1 (n=140) was used to determine internal consistency and validity of the CFFS-DLV and obtained from a larger, multicentre study on

the incidence and long-term follow-up of ABI in the Netherlands.[2] In that study, performed in 2010, 1881 patients aged 0-24 years with a hospital-based diagnosis ABI made in 2008 or 2009 were identified by means of a review of the medical records of the emergency ward databases and the patient administrations of 3 major hospitals: the Erasmus University Hospital in Rotterdam, and the Haga Hospital The Hague and Medical Centre Haaglanden, The Hague.[2] For the patient selection the following diagnoses codes were used: minor head injury, traumatic brain injury, concussion, skull/brain trauma, neurological trauma, epilepsy, brain tumour, stroke, infections (meningitis/encephalitis) and post anoxia. In both cohorts, the following basic characteristics of the participants were registered: age (years), sex, cause (TBI or NTBI) and severity. Severity of TBI was scored using the Glasgow Coma Scale (GCS)[23] or the paediatric version of the GCS[24] at the time of presentation in the emergency room. TBI was considered mild if the GCS was 13-15, moderate if the GCS was 9-12 or severe if the GCS was < 9.[25] The severity of NTBI, determined at the time of discharge after the first admission to the hospital for this particular problem, was scored by means of an adapted version of the modified paediatric Rankin Scale (mRS).[26] In addition, for NTBI, the underlying diagnosis was recorded (epilepsy, brain tumour, stroke, infections (meningitis/ encephalitis), post anoxia or otherwise (non-traumatic diagnosis).

For the present study, initially both the group 4-12 years and the group 13-20 years were stratified for the year of onset (2008 or 2009), type (TBI or NTBI) and severity (mild-moderate-severe) of injury. Four hundred and thirty-three patients were subsequently selected: all severe TBI and NTBI were invited, mild and moderate TBI and NTBI were selected at random via select cases, option select random cases in SPSS[27]. Selected patients were subsequently invited by regular mail to undergo an assessment approximately two years after onset of ABI.
Cohort 2 was used to determine test-retest reliability of the CFFS-DLV and comprised patients with ABI. They were recruited by inviting parents of patients diagnosed with ABI, who were treated at the outpatient clinic of a Rehabilitation Centre because of physical and/ or neuropsychological problems. They were all in the age group between 4 and 22 years and living at home.

Assessment methods

To determine the internal consistency and validity of the CFFS-DLV, the instrument and all other questionnaires were administered once to parents/caregivers of patients in cohort 1, prior to a medical neurological and neuropsychological examination of their child. For the assessment of the reliability, the CFFS-DLV was sent by regular mail to the parents of 35 children and adolescents with ABI (cohort 2). After they returned the questionnaire, a second CFFS-DLV was sent. The maximum time between filling in the first and second CFFS-DLV

was 2 weeks, as 'reasonable compromise between recollection bias and unwanted (on the part of the investigator) clinical change'.[28] In case the questionnaires were not returned, a reminder was sent after 3 weeks for the first administration and after 1 week for the second administration. Children completed the CAPE[29] after the neurological and neuropsychological examination. Socio demographic data of the patients (age, sex) and caregivers (relation to the child) and injury data (type, severity) were obtained from medical records.

Apart from the CFFS, the following questionnaires were administered: The PedsQL (Paediatric Quality of Life Inventory)[25] is an instrument measuring health related quality of life (HRQOL). Up to 40% of children are identified as having poorer quality of life after TBI.[31-33] The PedsQL is previously used or recommended in children after TBI.[18,30, 32, 24, 35] It comprises 23 items, divided over 4 subscales: Physical Functioning, Emotional Functioning, Social Functioning, and School Functioning. To create a Total Scale Score the mean is computed as the sum of all the item scores over the number of items answered. For ease of interpretability, items are reversed scored and linearly transformed to a 0-100 scale, so that higher scores indicate better HRQOL (Health-Related Quality of Life). The subscales include Physical Functioning and Psychosocial Functioning (Emotional, Social and School Functioning), both with a score range of 0-100. The PedsQL has 4 versions: for age categories 5-7, 8-12, 13-18 and 19-23 years old, both with a version for children or youth and for parents. The reliability and validity of the PedsQL is well demonstrated in several school[36] and clinical populations, e.g. children and adolescents with Cerebral Palsy and cancer.[37,38] The PedsQL Total and subscale scores were chosen as core outcome to determine concurrent validity of the CFFS-DLV. For the present study, only the parent version of the PedsQl was used to determine concurrent validity with the CFFS-DLV, given that the CFFS is a parent-reported measure.

The PSOM (Paediatric Stroke Outcome Measure)[39] measures neurological outcome regarding 5 areas of functioning: right sensorimotor, left sensorimotor, language production, language comprehension, and cognitive/behavioural. An overall Deficit Severity Score (DSS) of normal-mild-moderate-severe, as indicator of actual level of functioning is based on the combination of these scores, with a score range of 0-10. The PSOM was found to be a valid and reliable outcome measure in paediatric stroke.[40]

The CAPE (Children's Assessment of Participation and Enjoyment)[28] measures self-reported participation in recreation and leisure activities outside school activities. There are three levels of scoring for the CAPE: overall participation scores, scale scores for five types of activities (recreational, active physical, social, skill-based, self-improvement) on five dimensions of participation: diversity, intensity, experienced pleasure, with whom and where. The CAPE was found to be reliable and valid in children and adolescents (6-18 years old) with physical disabilities.[28,41] For the present study, only the diversity ('which activities does the child do') and intensity ('how often does a child do activities') dimensions of the CAPE were taken into account.

Analysis

Comparisons of the socio demographic characteristics and the CFFS-DLV scores between cohorts 1 and 2 were done by means of the Mann-Whitney U test or Chi-Square test, where appropriate. Internal consistency of the CASP-DLV, CAFI-DLV, and CASE-DLV was determined by computing Cronbach's alpha using the data from cohort 1.

'Better and best level of functioning' and 'worse and worst level of functioning' were determined by counting the number of respondents with a highest or lowest possible score on the CASP-DLV, CAFI-DLV and CASE-DLV. For the CASP, a higher score indicates a better level of functioning, whereas for the CAFI and CASE a lower score indicates a better level of functioning.

Concurrent validity was determined by means of Spearman Rank Correlation Coefficients (r) between CASP-DLV, CAFI-DLV, CASE-DLV on the one side and PedsQL, PSOM, and CAPE on the other side. We expected that the correlations would be moderate to strong, especially between CASP-DLV and PedsQL and CAFI-DLV and PSOM. In general, r<0.40 is considered as weak correlation, r=0.41-0.60 moderate, r=0.61-0.80 good and r >0.81excellent.[37] To examine if age would affect concurrent validity, the correlations of the CASP-DLV, CAFI-DLV and CASE-DLV total scores and the PedsQL parent version were repeated for patients in the age groups 5-14 and 15-22 separately.

Intra Class Correlation Coefficients (ICC) were computed to investigate the test-retest reliability[38] of the CFFS-DLV, using the total scores of the CASP-DLV, CAFI-DLV and CASE-DLV from cohort 2. Differences between the initial test and retest scores were analysed by computing the difference with the 95% confidence interval and by applying the Wilcoxon-Signed-Rank test.

RESULTS

Review expert panel

The expert panel found no items to be irrelevant in the Dutch culture. However, the three parents who completed the CFFS-DLV suggested to briefly explain the term 'participation' in the introduction and improve the translation of the word 'community' into the Dutch language. These suggestions were discussed with the expert panel and agreed upon. Furthermore the expert panel had no remarks regarding the readability and clarity of the questionnaire.

In addition, the expert panel suggested 2 aspects which were considered relevant but currently not included the CAFI: 'planning and organizing' (e.g. being on time, cleaning room) and 'language comprehension' (e.g. understanding of written or spoken language). The expert panel also noted 'Preferred activities in leisure time?' as missing in the open ended items in part 2 (child) and 4B (family). These comments were passed on to the original developer of the CFFS.

Patients

Two hundred and forty-seven (56%) patients responded to the invitation by regular mail to undergo an assessment approximately two years after the onset of ABI. Non-response was partly due to inaccuracy of the address information: of 68 patients the Patient Information Form was returned with 'wrong address'. Of the 247 responders, 147 children and parents agreed to participate. Main reasons not to participate were 'too burdensome', 'not interested due to lack of problems or lack of time' and comorbidity (psychiatric). Of these 147 participants, 135 completed the CFFS-DLV and at least one other questionnaire. In total 114 children underwent a neurological examination on an outpatient clinic of the participating hospitals, including the PSOM and 65 of them gave consent for a home visit to administer additional questionnaires.

With respect to cohort 2, 27 of the 35 invited patients returned two questionnaires (cohort 2). The clinical characteristics of the participants in cohorts 1 and 2 are shown in Table I.

Overall, cohort 1 counted more male patients (52% vs. 33%) and more patients diagnosed with 'mild' ABI (75% vs. 22%) than cohort 2.

Table I Characteristics of patients with acquired brain injury in a study on the validation of the Child and Family Functioning Survey (-Dutch Language Version)

		Cohort 1 (n=140)	Cohort 2 (n=27)	p-value[1]
Age, years; median (range)		14 (5-22)	16 (7-22)	0.016
Male sex; number (percentage)		73 (52.1)	18 (33.3)	0.129
Cause and severity;				
Traumatic	Total; number (percentage of total ABI)	106 (76)	17 (63)	0.170
	Mild; number (percentage of total TBI)	79 (75)	3 (18)	
	Moderate	12 (11)	5 (29)	
	Severe	13 (12)	9 (53)	
	Unknown	2 (2)	0 (0)	
Non-traumatic	Total; number (percentage of total ABI)	34 (24)	10 (37)	<0.001
	Mild; number (percentage of total TBI)	26 (76)	3 (30)	
	Moderate	7 (21)	1 (10)	
	Severe	1 (3)	6 (60)	
	Unknown	0 (0)	0 (0)	
Respondents	number (percentage) mother/father/ other/patient/unknown;	94 (67) / 25 (18)/ 1 (1) / 2 (1) / 18 (13)	24 (89) / 1 (4) / 2 (7) / 0 (0) / 0 (0)	
CFFS-DLV[2] parent reported; median (range)				
CASP[2]	Total (range 0-100)	98.8 (30.0-100)	82.5 (40.0-100)	<0.001
	Home (0-100)	100.0 (29.2-100)	83.3 (54.2-100)	<0.001
	Community (0-100)	100.0 (25.0-100)	75.0 (37.5-100)	<0.001
	School (0-100)	100.0 (20.0-100)	85.0 (0.0-100)	<0.001
	Home & Community Living (0-100)	100.0 (20.0-100)	85.0 (25.0-100)	0.001
CAFI[3]	Total (33-100)	37.8 (33.3-84.4)	58.9 (35.6-86.7)	<0.001
CASE[3]	Total (0-100)	33.3 (33.3-59.3)	39.8 (33.3-64.8)	<0.001
PedsQL[2]	parent reported; median (range) (n = 135)			
	Total (0-100)	83.7 (40.8-100.0)		
	Physical (0-100)	93.8 (18.8-100.0)		
	Psychosocial (0-100)	78.6 (36.7-100.0)		
PSOM[2]	professional reported (0-4.5); median (range) (n = 107)	0.5 (0.0-4.5)		
CAPE[2]	child reported; mean (standard deviation) (n=65)			
	Diversity (0-55)	27.0 (15.0-40.0)		
	Intensity (1-7)	2.4 (1.5-3.8)		

[1] p-value of Mann-Whitney U test or Chi Square test

[2] CFFS-DLV= Child and Family Functioning Survey (-Dutch Language Version); CASP= Child and Adolescent Scale of Participation; CAFI= Child and Adolescent Factors Inventory ; CASE=Child and Adolescent Scale of Environment; PedsQl= Paediatric Quality of Life Inventory; PSOM= Paediatric Stroke Outcome Measure; CAPE= Children's Assessment of Participation and Enjoyment

Internal consistency and floor and ceiling effects

Using the data from cohort 1, Cronbach's alpha was 0.95 for the CASP-DLV, 0.89 for the CAFI-DLV and 0.83 for the CASE-DLV. The mutual correlations between CASP-CAFI and CAFI-CASE were moderate (-0.43 and 0.55, respectively) and between CASP-CASE low (-0.24). The average total scores of cohort 1 were significantly better than those of cohort 2 (CASP-DLV 92.4 versus 79.5, CAFI-DLV 39.6 versus 58.9 and CASE-DLV 34.6 versus 42.9) (all p-values <0.001, Mann-Whitney U test). Table II shows that for the CASP-DLV the best level of functioning (highest score) was seen in 63 (45%) of the patients in cohort 1.

Table II Numbers (%) of patients with a highest or lowest possible score[1] on the CASP-DLV, CAFI-DLV and CASE-DLV[2] total scores

	highest possible score		lowest possible score	
	COHORT 1	COHORT 2	COHORT 1	COHORT 2
CASP-DLV (0-100)	63 (45)	3 (11)	1 (0.7)	1 (3.7)
CAFI-DLV (33-100)	0 (0)	1 (3.7)	46 (32.9)	1 (3.7)
CASE-DLV (0-100)	0 (0)	2 (7.4)	66 (47.1)	1 (3.7)

[1] for the CASP a higher score indicates a better level of functioning, whereas for the CAFI and CASE a lower score indicates a better levels of functioning

[2] CASP-DLV= Child and Adolescent Scale of Participation (-Dutch Language Version); CAFI-DLV= Child and Adolescent Factors Inventory (-Dutch Language Version); CASE-DLV= Child and Adolescent Scale of Environment (-Dutch Language Version)

Overall, the CASP-DLV, CAFI-DLV and CASE-DLV total scores showed significant correlations with the parent version of the PedsQL (total score) and the PSOM (total score). The Spearman rank correlation coefficients of the domain scores of the CASP-DLV, CAFI-DLV and CASE-DLV with the PedsQL (total score) varied from 0.33 to 0.64 (all p-values <0.05). The correlations between CASP-DLV and PedsQL and CAFI-DLV and PSOM were, in contrast with what we suspected, not relatively higher. Repetition of the analysis for the correlations of the CASP, CAFI and CASE total scores with the PedsQL parents for the age groups 5-14 years and 15-22 years separately showed overall similar results in both age groups, with slightly stronger associations in the older patient group. Neither the CASP-DLV, CAFI -DLV nor CASE-DLV total or subscale scores were associated with the CAPE dimension scores diversity or intensity.

Concurrent validity

Table III shows the correlations between the CASP-DLV, CAFI-DLV and CASE-DLV and other measures of functioning, participation and environmental factors.

Table III Concurrent validity of the CFFS-DLV[1]

	Parent reported		Patient reported	
	PedsQL parents total (n=135)	PSOM medical neurological (n=114)	CAPE patient participation diversity (n=64)	CAPE patient participation intensity (n=64)
CASP[1] total	0.451*	-0.497*	0.082	0.050
CASP home	0.382*	-0.557*		
CASP community	0.410*	-0.444*		
CASP school	0.416*	-0.523*		
CASP home & community living	0.330*	-0.309**		
CAFI[1] total	-0.738*	0.396*	-0.035	-0.045
CAFI cognitive	-0.635*	0.286**		
CAFI psychological	-0.634*	0.328*		
CAFI physical	-0.593*	0.313*		
CAFI sensory	-0.515*	0.304*		
CASE[1] total	-0.626*	0.480*	0.032	0.072

* Correlation is significant at the 0.001 level (2-tailed)

** Correlation is significant at the 0.05 level (2-tailed)

1 CFFS-DLV= Child and Family Functioning Survey (-Dutch Language Version); CASP= Child and Adolescent Scale of Participation; CAFI= Child and Adolescent Factors Inventory; CASE= Child and Adolescent Scale of Environment; PedsQl= Paediatric Quality of Life Inventory; PSOM= Paediatric Stroke Outcome Measure; CAPE= Children's Assessment of Participation and Enjoyment

Reliability

Table IV shows the CFFS test-retest results for cohort 2.

The best levels of functioning for the CAFI-DLV and CASE-DLV (lowest scores) were seen in 46 (33%) and 66 (47%) in cohort 1, respectively.

Table IV Test-retest reliability of the CASP-DLV, CAFI-DLV and CASE-DLV[1] total scores

variable	Median score (range) 1st administration	Median score (range) 2nd administration	Mean difference (95% CI) Paired t-test	P value Wilcoxon[1]	ICC[2] (95% CI)
CASP-DLV[3]	82.5 (40.0-100.0)	78.8 (42.5-100.0)	2.3 (-1.7 to 6.2)	0.415	0.90 (.079-.096)
CAFI-DLV[3]	55.6 (35.6-86.7)	53.3 (33.3-82.2)	1.5 (-0.8 to 3.7)	0.189	0.95 (.089-.098)
CASE-DLV[3]	39.8 (33.3-64.8)	40.7 (33.3-55.6)	0.8 (-2.0 to 3.7)	0.632	0.81 (.533-.916)

1 significant at the 0.01 level; ICC average measures

2 ICC= Intraclass Correlation Coefficient; CI= Confidence Interval

3 CASP-DLV= Child and Adolescent Scale of Participation (-Dutch Language Version); CAFI-DLV= Child and Adolescent Factors Inventory (-Dutch Language Version); CASE-DLV= Child and Adolescent Scale of Environment (-Dutch Language Version)

Overall, there were no statistically significant differences between the first and the second measurement. Test-retest reliability was found to be high for the CASP-DLV and CAFI-DLV and moderate for the CASE-DLV.

DISCUSSION

This study showed that translation of the original English version of the CFFS into the Dutch language (CFFS-DLV) did not compromise the psychometric qualities of this survey, which is developed to monitor long term outcome of children and youth with ABI.

The results of this study are largely in line with those obtained in a study performed by Bedell[16], who was the developer of the CFFS. Bedell[16] included patients with a range of disabling conditions (n=260) as well as without disabilities (n=53). Regarding test-retest reliability Bedell[16] reported similar results for the CASP (0.94 vs. 0.90 in the present study) and CASE (0.75 vs. 0.81 in the present study) and somewhat less favourable results for the CAFI (0.68 vs. 0.95 in the present study). The internal consistency of the CASP, CAFI and CASE as reported by Bedell[16] was high (Cronbach's alpha 0.96, 0.86 and 0.91, respectively) and comparable to our study (0.95, 0.89 and 0.83 respectively). With respect to validity, in the previous study correlations with the Paediatric Evaluation of Disability Inventory (PEDI)[44] were computed, with the correlation coefficients being 0.75, 0.31 and 0.31 for the CASP, CAFI and CASE, respectively. In contrast, in our study the PedsQL (parents version) was used for comparison, yielding a weaker correlation for the CASP (0.45) and stronger correlations for the CAFI and CASE (0.74 and 0.63, respectively).

Concerning the mutual correlations among the CASP, CAFI and CASE, the correlation coefficients varied between 0.24 and 0.55 in the present study and 0.55-0.58 in the previous study.[16] These associations underline the interdependence of limitations on the level of participation (CASP), body functions and structures (CAFI) and environmental factors (CASE) in this patient group.[13,16]

Our additional effort to compare the parent-reported health-related problems with functions (CAFI-DLV) with a professional's score (PSOM), a stroke specific outcome measure, resulted in evidence for concurrent validity.

The incomplete associations between the CAFI-DLV, PSOM and PedsQL, each with a somewhat different scope or perspective, indicate that the three instruments can be used supplementary to each other in measuring the (impact of) limitations in body structure and functions, activities and participation in children and adolescents with ABI and their families. Previous research,[28,41] demonstrated relations between the CAPE scores with level of impairments and environmental problems in children with Cerebral Palsy. The absence of an association of the CASP with the CAPE as seen in the present study could possibly be

explained by the CASP focusing on participation restrictions (in broad categories) whereas the CAPE measures the range, diversity and frequency of participation (in discrete activities), which may be different aspects. The range and how often one participates may be based on factors such as child/family preferences and family resources. In addition, the 55 CAPE-items require reading, language and (sustained) attention skills, that are frequently limited after ABI, and the single version may not fit all age ranges.[45] Finally, important contemporary activities, such as social media and gaming, are lacking. Moreover, the perspectives of parents and children with respect to participation may be different. Indeed, overall better correlations of the CAPE with other outcome measures were seen in previous studies (Lawson, Anaby) in which the CAPE was compared only with child-reported instruments.
A further examination of the CAPE in research in ABI, for example in relation to the PedsQL and PSOM was advocated.

A relatively high proportion of patients with the best or worst possible score limits the discriminative qualities of a questionnaire, for example with respect to its sensitivity to change. In this study, the CFFS-DLV demonstrated high percentages of patients with the best possible score for the CASP-DLV, CAFI-DLV and CASE-DLV. This result is likely to be explained by the selection of patients, yielding a population with predominantly mild ABI, not requiring treatment. Further research in larger cohorts with children and adolescents with clinically significant symptoms of ABI at different time points across recovery is required to evaluate the potential of the CASP-DLV, CAFI-DLV and CASE-DLV to detect improvement or regression over time.

Parents are important observers,[46,47] however may be limited in their ability to value the mental state and experience of participation restrictions and quality of life of another person, despite the fact that they live closely together. In monitoring outcome at the level of participation it is recommended to merge different perspectives, due to discrepancies regarding the assessment of participation of children and youth with ABI between patients, parents or caregivers and professionals.[45,46] A youth version of the CASP (CASP-Y)[48] for the age group 8-21 years has recently been validated and will be considered in the future research projects to gain children's perspectives about their own participation. In accordance with Galvin[11] the addition of supplement for an 'outside family observer' (teacher, colleague, friend) as well, to get a more comprehensive impression of the functioning of the child seems useful. A selection of CFFS-DLV items (part 4A: items 3,4,5; 4B: 2,3; 5: 1,2) can be used for this purpose. Moreover, a mixed method design, integrating more qualitative and quantitative information, as suggested by van Tol et al.[49] may be a next step in participation studies in ABI. In addition to closed questions, open-ended questions such as in the CFFS part 1 (personal situation), 4 (family impact) and 5 (actual needs and concerns) or an interview[50] could enable parents to describe the situation more precisely and specifically. Personalised information is meaningful for clinicians to improve understanding of parents perspective but

requires qualitatively (or content) analyses if used in research.

This study has a number of limitations. First, the generalizability of the results is limited by the sample size of n= 108 and n=27 for the validity and reliability studies, respectively. Moreover, the characteristics of the patients included in the two cohorts differed significantly. The largest cohort included children who were not referred for treatment of ABI and accordingly comprised relatively many children with no or few consequences of ABI, whereas in the smaller cohort the patients were recruited from the rehabilitation setting, with the majority of children having severe ABI. Given these differences, it remains unclear whether the results obtained within one of the cohorts can be generalised to the other cohort. To overcome these shortcomings, a larger scale and longitudinal study including sufficient numbers and proportions of children with mild, moderate and severe ABI would be needed. Such a design would not only allow for a further examination of the measurement properties as studied in the present project, but also of the responsiveness to change on the group and individual level.

Another limitation was the use of the PSOM-SNE,[39] which was, although commonly used in clinical practice after non-stroke NTBI and TBI and recommended as outcome measure,[40,51,52] primarily designed to assess medical neurological functioning of children and youth after stroke. Despite this shortcoming, it was used in the absence of a specific instrument for these populations.

Moreover, no specific instrument measuring participation was available as gold standard for comparison with the CFFS-DLV. In fact the CASP (participation), CAFI (functions) and CASE (environmental factors) have different scopes. Finally, the sensitivity to change of the CFFS has not been studied yet. Finally, although the majority of parent-responders were mothers, it cannot be ruled out that the results of this study are influenced by the type of respondent (mother, father or guardian). To further examine this effect, a different study design and study size would be needed.

In conclusion, the CFFS-DLV is a promising instrument to measure long term outcome of young people with ABI in the Netherlands and Dutch-speaking Belgium. However, larger, prospective studies are needed to confirm and further explore its measurement properties.

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Declaration of interest

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