ORIGINAL ARTICLE

Who best to make the assessment? Professionals' and families' classifications of gross motor function in cerebral palsy are highly consistent

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Aim: To determine the reliability of family assessment for the Gross Motor Function Classification System (GMFCS) for children with cerebral palsy in the UK.

Methods: Families of a complete geographically defined population of children with cerebral palsy between 6 and 12 years old were identified from the *4Child* epidemiological database. Postal surveys were conducted with the families and any of the child's health professionals that were nominated by the families.

Results: Families of 129/314 eligible children took part in the study (41%). The indices of agreement and reliability between families and professionals were also equivalent to those observed between the professionals ($\kappa=0.5$, ICC ≥ 0.9). Reliability coefficients were higher when more of the professionals classified children using direct observation rather than only reviewing their clinical records.

Conclusions: Despite excellent reliability, families and professionals did not always agree exactly on a child's GMFCS level. Classifications may differ due to children's varying performance in different environments, in which case families will almost certainly know their children's ability in a broader range of settings. The indices of reliability of family assessment for the GMFCS meet the recommended criteria for use with individuals and groups, indicating that the method is suitable for use in research studies and clinical practice.

The Gross Motor Function Classification System (GMFCS) was developed in response to the need to have a standardised system for describing and classifying the severity of movement disability among children with cerebral palsy.¹ Palisano and colleagues used the underlying construct of self-initiated functional abilities in sitting and walking and the need for assistive devices, such as walkers or wheelchairs, to develop the GMFCS, and unlike previous systems,²⁻⁴ they systematically tested its validity and reliability.¹⁻⁵ The GMFCS describes the movement ability of children with cerebral palsy in one of five ordinal levels. Children's abilities in each level are currently described across four age bands: <2 years, 2-4 years, 4-6 years, and 6-12 years, with an adolescent age band currently under development. Children in level I can perform all the activities of their age matched peers, albeit with some difficulty with speed, balance, and coordination; children in level V have difficulty controlling their head and trunk posture in most positions and achieving any voluntary control of movement (box 1).

Since its publication the GMFCS has become established as the principal classification system for describing the severity of motor disability for children with cerebral palsy.⁶ The classification system has had excellent uptake internationally and across the spectrum of healthcare professions by providing a system for clearly communicating about children's movement ability. The GMFCS has been used to stratify children by their ability for both observational and experimental research and as an outcome of neonatal clinical trials.⁶ A four year longitudinal study conducted with more than 650 children in Ontario, Canada, enabled motor development curves to be described for each GMFCS level.⁷ The curves show clinically meaningful and significant differences in motor development between GMFCS levels and can therefore be used to discuss children's prognosis, such as to predict a younger child's potential to walk.⁸ The

Ontario Motor Growth (OMG) Study further enhances the validity of the GMFCS, confirming the system as the current gold standard for describing gross motor function in children with cerebral palsy. Reliability, which is the topic of this paper, describes how consistent or reproducible classifications are when made by different observers, or between classifications made on different occasions.

In a previous study in Canada, family assessment for the GMFCS was shown to be highly reliable compared to classifications made by therapists in the OMG Study (ICC >0.9).⁹ However, in that study, many families indicated that they had previously discussed the GMFCS with a health professional. The findings of that study might therefore have overestimated the reliability of the family assessed method and the findings may not be generalisable to the UK. As part of a broader survey using family assessed instruments to measure the "activities and participation" of children with cerebral palsy, as defined in the International Classification of Functioning Disability, and Health (ICF),¹⁰ the present study explored the reliability of family assessment using the GMFCS in the UK.

METHODS

The source of the study population was the *4Child* Four Counties Database of Cerebral Palsy, Vision Loss and Hearing Loss in Children (formerly known as ORECI) in the UK. The population eligible for inclusion in the survey were families of children with cerebral palsy born to a mother who at the time of the child's birth was resident in the defined geographical area known as the Thames Valley Strategic Health Authority (TVSHA), which comprises Berkshire, Buckinghamshire, and Oxfordshire, three of the four counties covered by *4Child*. The children were between 6 and 12 years old when the survey was conducted in 2003. The study was approved by Oxfordshire research ethics committee, permitting the

Box 1: Descriptions of Gross Motor Function Classification System (GMFCS) levels between 6th and 12th birthday¹

- **Level I.** Children walk indoors and outdoors, and climb stairs without limitations. Children perform gross motor skills including running and jumping, but speed, balance, and coordination are reduced
- **Level II.** Children walk indoors and outdoors, and climb stairs holding onto a railing, but experience limitations walking on uneven surfaces and inclines, and walking in crowds or confined spaces. Children have at best only minimal ability to perform gross motor skills such as running and jumping
- **Level III.** Children walk indoors or outdoors on a level surface with an assistive mobility device. Children may climb stairs holding onto a railing. Depending on upper limb function, children propel a wheelchair manually or are transported when travelling for long distances or outdoors on uneven terrain
- **Level IV.** Children may maintain levels of function achieved before age 6 or rely more on wheeled mobility at home, school, and in the community. Children may achieve self-mobility using a power wheelchair
- **Level V.** Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. Children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations

The standard user instructions and complete guide to the GMFCS are available at www.fhs.mcmaster.ca/canchild

families to be traced and those residing in the Thames Valley to be contacted; the Central Manchester multicentre research ethics committee provided approval to contact families who had migrated outside the Thames Valley area. Current addresses and general practitioner (GP) details for children were traced using the NHS National Strategic Tracing Service. Before families were contacted, their GPs were offered the opportunity to decline access if they felt it would have been inappropriate to contact the family; 11 were omitted on this basis. The families of children not otherwise excluded were invited to take part in the study; those who consented were mailed the questionnaires.

The same GMFCS family questionnaire used in the Canadian survey⁹ was used in the UK survey without any changes. A separate page asked families to nominate some of their child's health professionals such as therapists, paediatricians, or orthopaedic surgeons. The nominated professionals were subsequently surveyed by mail to obtain their assessment of the child's movement ability using the GMFCS standard instructions. Health professionals were also asked to indicate whether they had made their assessment by "direct observation", by "reviewing the child's records", or a "mixture of both". Prepaid return envelopes were provided for all questionnaires; reminder letters were mailed if no response was received after four weeks and then again after a further two weeks. Finally, in order to obtain a classification using the GMFCS for as many children in the eligible

population as possible, a further one-off letter was mailed to families who had not responded which included only the GMFCS questionnaire and an explanatory letter. Families who participated were surveyed again between three and six months later for a second rating of the GMFCS to enable a test-retest analysis.

All data were entered twice and discrepancies corrected. The cleaned and coded data were imported into SPSS (version 11). Details of each child's impairment were extracted from the *4Child* database including type and distribution of cerebral palsy and the presence of seizures, or hearing or vision impairments. Indices of children's intellectual delay and lower limb function were also available from *4Child*. The Indices of Multiple Deprivation (IMD 2004)¹¹ were derived using the families' postcodes at the time of the study. The statistical significance of any differences in the proportion of children with various impairments among full and non-participants was compared using the χ^2 test for proportions.

Agreement between assessments was corrected for chance using Cohen's kappa coefficient (κ) and reliability was determined using the intraclass correlation coefficient (ICC), which is equivalent to a weighted kappa when calculated using quadratic weights.¹³ Interpretation of kappa statistics are recommended as "poor" when lower than 0.4, "fair to good" between 0.41 and 0.8, and "almost perfect" above this value.¹³ Reliability coefficients are directly related to the variability in the population in which they are used;¹⁵ however, coefficients exceeding 0.7 are commonly regarded as reliable for population based research and coefficients exceeding 0.9 are regarded as reliable for use clinically with individuals.¹⁴⁻¹⁶

RESULTS

Invitations were mailed to the families of 321 surviving children in the eligible population. Seven invitations were returned by the postal service as undeliverable. Of the 314 families who could therefore have received the invitation, the families of 129 children fully participated in the survey (41%). The mailing to families who had not specifically declined achieved a further 51/127 responses (40%). In total, there were 175/314 children (56%) for whom families returned a questionnaire indicating a single GMFCS level. Fully participating families nominated between none and five of their child's health professionals depending on which clinical services the children were receiving. The subsequent survey of health professionals requesting their assessments of children using the GMFCS achieved 100/104 responses from physiotherapists (96%), 80/83 responses from paediatricians (96%), and 53/58 responses from orthopaedic surgeons (91%).

Sample characteristics

A comparison of the characteristics of the children of families who fully participated and those who did not is shown in table 1. There were no statistically significant differences between the children of families who participated and those who did not take part fully in terms of their age, sex, type of cerebral palsy, and associated impairments. However, children of the fully participating families had relatively less severe intellectual delay and slightly better lower limb function in the middle of the "lower limb function" scale used by *4Child*; about a third of children in both groups were designated on this scale as not walking.

Half of fully participating families lived in areas corresponding to the least deprived national quintile of the Indices of Multiple Deprivation 2004, and only a few were residing in the most deprived areas (table 2). There were 12 children for whom area deprivation data could not be derived, of which two were among the participants, and were excluded from

Table 1 Summary of key characteristics of the children of full and non-participants

	Full participants (n = 129) Mean age 9.9 (SD 1.9) y		Non-participants (n = 208) Mean age 9.8 (SD 2.1) y		p value
	n	%	n	%	
Male	72	56	113	54	0.13
Type of cerebral palsy					0.52
Spastic	108	84	171	82	
Bilateral	62	48	113	54	0.28
Hemiplegia	46	36	58	28	0.13
Dyskinetic	15	12	22	11	
Ataxic	3	2	4	2	
Unclassified	3	2	12	6	
Associated impairments					
Seizures	28	23	45	23	0.89
Hearing loss	5	4	6	2	0.61
Vision loss	25	19	32	15	0.34
IQ <50	26	23	37	21	
IQ 50–69	13	11	27	16	0.07
IQ >70	74	65	98	66	
Lower limb function					0.05
Walks fluently	14	11	11	5	
Functional, not fluent	52	40	74	35	
Restricting lifestyle	16	12	45	21	
Not walking	40	31	70	33	
Missing	7		8		

this analysis. While there was a higher response from families resident in areas corresponding to the least deprived quintile, the difference between the proportion of full and non-participants in each deprivation quintile was not statistically significant.

Agreement

The assessments for the GMFCS made by families and physiotherapists agreed exactly for 64% of the children; both families and paediatricians and families and orthopaedic surgeons agreed exactly for 59% of the children. Overall, the chance corrected agreement between families and physiotherapists was $\kappa = 0.54$ (95% CI 0.42 to 0.66), between families and paediatricians was $\kappa = 0.50$ (95% CI 0.36 to 0.63), and between families and orthopaedic surgeons was $\kappa = 0.47$ (95% CI 0.30 to 0.64). Paediatricians and physiotherapists agreed exactly on children's GMFCS level 72% of the time ($\kappa = 0.65$, 95% CI 0.52 to 0.79); orthopaedic surgeons and physiotherapists agreed exactly for 50% ($\kappa = 0.38$, 95% CI 0.17 to 0.59); and orthopaedic surgeons and paediatricians agreed exactly for 50% ($\kappa = 0.38$, 95% CI 0.19 to 0.55).

Reliability

The reliability of families' classifications relative to physiotherapists was ICC = 0.92 (95% CI 0.90 to 0.93) (table 3), relative to paediatricians was ICC = 0.90 (95% CI 0.88 to

0.92), and relative to orthopaedic surgeons was ICC = 0.87 (95% CI 0.82 to 0.90). The coefficients of reliability (ICC) among professional groups ranged from 0.82 to 0.92 (table 4). For the test-retest study, the indices of agreement and reliability between 79 families who provided classifications three months apart were very high: $\kappa = 0.92$ (95% CI 0.85 to 0.99) and ICC = 0.98 (95% CI 0.97 to 0.99).

The majority of physiotherapists made their assessments by direct observation (38%) or used a mixture of observation and record review (54%), while only (8%) of ratings were made solely by reviewing the records. Paediatricians used direct observation (24%) and the mixed method (48%) less often than physiotherapists and more of them (28%) were dependent on reviewing the child's records. Orthopaedic surgeons depended almost entirely on reviewing children's records (86%) or the mixed method (10%), with only ratings (4%) made by direct observation. The reliability coefficients for classifications made by families compared to professionals were slightly higher when a greater proportion of the professionals indicated using direct observation. Only 13/129 parents (10%) indicated that they had discussed the GMFCS with a health professional.

DISCUSSION

Of the 180 classifications provided by families using the GMFCS, only five did not indicate a single level. This suggests

Table 2 Comparison of full and non-participants by deprivation in area of residence using national quintiles of the Indices of Multiple Deprivation 2004

IMD 2004 national quintiles	Full participants n = 127		Non-participants n = 198		p value
	n	%	n	%	
Quintile I (least deprived)	67	53	76	38	
Quintile II	23	18	49	25	
Quintile III	17	13	36	18	0.11
Quintile IV	17	13	27	14	
Quintile V (most deprived)	3	2	10	5	

Table 3 Comparison of GMFCS levels reported by families and physiotherapists

	Families					Total
	I	II	III	IV	V	
Physiotherapists						
I	17	18	1			36
II	1	16	2			19
III		2	8	5		15
IV			2	8	5	15
V				–	14	14
Total	18	36	13	13	19	99

ICC=0.92 (95% CI 0.90 to 0.93).

that this GMFCS questionnaire is easy to understand and that the descriptions of children's movement abilities are meaningful to families. In contrast to the Canadian study⁹ where more than a third of the families indicated having discussed the system with a health professional, only one in ten of the families in the UK study had done so. In fact, many of the health professionals in the UK informally indicated that they were also unfamiliar with using the GMFCS until taking part in this study.

The response from health professionals providing their classification of children's movement abilities using the GMFCS was exceptional, exceeding 90%. This high response might be attributable to a sense of obligation to the families who had nominated them personally. As families could only nominate professionals who were providing care for their child, statistical analyses were conducted as paired assessments for each child, firstly between families and each professional group, and then between each of the professional groups.

The indices of agreement observed in this study are slightly lower than those reported by the developers ($\kappa = 0.75$) in their initial study examining agreement between therapists for children between 2 and 12 years.¹ However, what is not reflected in the kappa statistic is that the most frequent disagreement was between GMFCS levels I and II, which is more evident in table 3. This concurs both with the developers' findings observing therapists¹ and the study conducted with families and therapists in Canada,⁹ that levels I and II were the most difficult to distinguish. Notably, half of the children that physiotherapists classified in level I were classified by their families in level II, i.e. less able, whereas the reverse situation was much rarer. A similar trend was observed between families and paediatricians. However, the opposite pattern occurred between families and orthopaedic surgeons, the surgeons having classified several children in level II that families classified in level I. As children in levels I and II do not use any walking aids the distinction depends more on the extent to which observers

know how children perform across different environments. This contrasts with children's best capability which professionals more often assess by minimising any limiting effect of the environment. Children in GMFCS levels III, IV, and V all use wheeled mobility depending on the environment and context; the typical circumstances of family life might be expected to be more challenging than adapted environs, such as at school or hospitals.

Having replicated the findings in a second study, the claim that family report for the GMFCS is reliable⁹ can be asserted more confidently and also now generalised to the UK, with the caveat that families and professionals do not always completely agree. Health professionals and families made their classifications using the GMFCS based on their knowledge of the child's movement abilities and the instructions provided. As the same child is being assessed, one source of measurement error could be the abilities of the observers. However, based on the reports by Palisano and colleagues¹⁷ and Tieman and colleagues,¹⁸ and in keeping with the ICF model, it is likely that some children move differently according to where they are, for instance at hospital, school, or in their home. So it could be that the same child's movement abilities are perceived and experienced by families and professionals as different because of the effect of the environment in which the child is observed. Almost certainly the family will have greater knowledge of the child's abilities generally, and across a wider range of environments than professionals. Notably, from the test-retest analysis, families' classifications were also shown to be highly consistent over time, changing little in a 3–6 month interval.

The reliability coefficient for classification of the GMFCS by families (0.9) meets the criterion suggested for using measures with individuals as well as for groups.¹⁶ In the clinical context, providing family centred services requires professionals to enter into partnership with families and recognise parents as the experts regarding their child's abilities and needs. This approach is typically associated with better health outcomes for both children and their parents.¹⁹ Gathering a classification from a family of their opinion of the child's abilities using the GMFCS may empower them and help them feel that their opinion matters. If this information were gathered prior to a consultation, any disagreement could then be discussed and might prove enlightening for either parent or professional, or indeed both.

For research purposes, some may prefer to continue seeking the professionals' view of children's abilities with the assumption that this is more objective. For scientific rigour, it is now clear that it is not crucial whether families or professionals classify children in research studies but authors of scientific papers should, for clarity, state explicitly in the methods section who undertook the classification. In addition, monitoring the reliability between families and professionals is important if professional assessment is used, especially as there would be minimal additional costs to do

Table 4 Summary of indices of agreement and reliability between family and professional classifications using the GMFCS

Observers	Number of children	Perfect and chance corrected agreement		Reliability ICC (95% CI)
		%	κ (95% CI)	
Families/physiotherapists	99	64	0.54 (0.42–0.66)	0.92 (0.90–0.93)
Families/paediatricians	79	59	0.50 (0.36–0.63)	0.90 (0.88–0.92)
Families/orthopaedic surgeons	51	59	0.47 (0.30–0.64)	0.87 (0.82–0.90)
Physiotherapists/paediatricians	65	72	0.65 (0.52–0.79)	0.92 (0.89–0.94)
Paediatricians/orthopaedic surgeons	43	50	0.37 (0.17–0.59)	0.82 (0.67–0.90)
Physiotherapists/orthopaedic surgeons	32	50	0.38 (0.19–0.55)	0.83 (0.75–0.86)

What is already known on this topic

- The GMFCS has become the standard way to describe the movement ability of children with cerebral palsy; classification is typically undertaken by therapists

so. Further exploration in this way will help to elucidate any potential systematic bias between families and professionals.

The moderate response to this survey must be acknowledged as a potential limitation to the generalisability of the findings. The key issues affecting response to the invitation were probably that families were unfamiliar with *4Child* and that the topic of the survey was not of sufficient interest. A better response would be anticipated when families are more familiar with the purpose of the survey such as prior to a clinical appointment or a research study in which they had already consented to take part. However, the extent of any response bias has been examined, and although children in the study might have been slightly more able than those who did not take part, no statistically significant differences were found between the characteristics of the full and non-participating children. The findings are therefore likely to be representative of the population in this study but, as the Thames Valley is generally a relatively prosperous region compared to the rest of the UK, it is not possible to determine how generalisable the findings are to regions with different area deprivation profiles. However, aside from literacy perhaps, there is no reason to suspect that families living in more socioeconomically deprived areas are likely to be less reliable in reporting their child's abilities given the simplicity of the language used.

It is also important to note that the reliability studies described have to date only included children between 6 and 12 years old and the GMFCS has several other age categories. Using modified descriptions of children's abilities for those ages, colleagues are examining the reliability of families classifying children between 2 and 4 years, and 4 to 6 years of age.

Conclusions

Families' classifications of their children's movement abilities using the GMFCS have been shown to be consistent with those of health professionals in studies conducted in both the UK and Canada. Families and professionals did not always agree exactly on a child's GMFCS level, particularly when professionals relied solely on reviewing children's records to make a classification; however, disagreement by more than one level was rare. As classification may differ due to children's varying performance in different environments, families will almost certainly know their children's ability across a broader range of settings. The indices of reliability of family assessment for the GMFCS meet the recommended criteria for use with individuals and groups, indicating that the method is suitable for use in research and to inform clinical practice.

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What this study adds

- Families' classification using the GMFCS is highly consistent with that of professionals, and may actually reflect children's gross motor performance across a broader range of settings

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