Disability and its relation with functional independence in children with cerebral palsy: an ICF study of preliminary clinical experience from Turkey

Mintaze Kerem Günel, Akmer Mutlu

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Research Report

Purpose: The purpose of this study was to analyze and to investigate correlation between impairments, activity limitations and participation restrictions in self care, mobility, communication, social relations, learning and applying knowledge as proposed in International Classification of Functioning, Disability and Health (ICF); and to examine the relation of ICF with functional independence in children with Cerebral Palsy (CP). Materials and methods: The study included 83 children with various types and severity of CP. Clinical type and extremity distribution of children were determined according to definitions adopted for European Classification of CP in Surveillance of Cerebral Palsy in Europe (SCPE). Gross Motor Function Classification System (GMFCS) and Bimanual Fine Motor Function (BFMF) were used for activity limitation and WeeFIM instrument for functional independence. In addition impairments and participation restrictions were investigated. Results: All children had at least one impairment. Bilateral spastic type of CP made up 81.6% of the total impairments. Spasticity occured in 93.7% of the children. There was a strong correlation of 0.82 between GMFCS and BFMF (p<0.01). Participation restriction and activity limitation strongly affected functional independence (p<0.001). Conclusion: ICF can be an appropriate model for our country if a common language in the rehabilitation team of children with CP may be provided and if its use becomes widespread around Turkey.

Key words: Cerebral palsy, Disability, Handicapped.

Serebral paralizili çocuklarda özür ve özürün fonksiyonel bağımsızlıkla ilişkisi: Türkiye'den ICF ile ilgili ilk klinik deneyim

Amaç: Bu çalışma, serebral paralizili (SP) çocuklarda Uluslararası Fonksiyon, Özür ve Sağlığın Sınıflandırmasına göre bozukluğu, aktivite limitasyonunu ve katılımdaki kısıtlılığı (kendine bakım, mobilite, iletişim, sosyal ilişkiler, öğrenme ve bilgiyi uygulama) analiz etmek, birbirleriyle korelasyonlarını araştırmak ve fonksiyonel bağımsızlık ile ilişkisini ortaya koymak amacıyla planlandı. Gereç ve yöntem: Bu çalışmaya çeşitli tip ve şiddetteki 83 SP'li çocuk dahil edildi. Çocukların klinik tip ve ekstremite dağılımları Avrupa SP sınıflandırmasına (SCPE) göre yapıldı. Gross Motor Fonksiyon Sınıflandırma Sistemi (GMFSS) ve Bimanuel İnce Motor Fonksiyon (BİMF) ölçümleri kullanılarak aktivite limitasyonları değerlendirildi. Bununla birlikte bozukluklar ve katılımdaki kısıtlılıklar da değerlendirildi. Sonuçlar: Tüm SP'li çocuklarda en az bir bozukluk mevcuttu. Toplam bozuklukların % 81.6'sı bilateral spastik tip SP'li çocuklara aitti. Çocukların %93.7'sinde spastisite vardı. GMFCS ve BİMF arasında 0.82 oranında yüksek korelasyon bulundu (p<0.01). Katılımdaki kısıtlılık ve aktivite limitasyonu ile fonksiyonel bağımsızlık arasında güçlü korelasyon bulundu (p<0.001). Tartışma: ICF, Türkiye'de rehabilitasyon ekibi arasında ortak dili oluşturulabilirse ve ülke genelinde kullanımı yaygınlaştırılabilirse artan ihtiyacı karşılamaya uygun bir sınıflamadır.

Anahtar kelimeler: Serebral Paralizi, Özür, Engel.

Research Report

M Kerem Günel Hacettepe University, Faculty of Health Sciences, Department of

Physical Therapy and Rehabilitation, Ankara, Türkiye PT, PhD, Assoc Prof

A Mutlu

Hacettepe University, Faculty of Health Sciences, Department of Physical Therapy and Rehabilitation, Ankara, Türkiye PT, MSc

Address correspondence to: Doç. Dr. Mintaze Kerem Günel Hacettepe University, Faculty of Health Sciences, Department of Physical Therapy and Rehabilitation, 06100 Samanpazari ankara, Türkiye E-mail: mintaze@yahoo.com

Cerebral palsy (CP) describes a group of motor disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occured in the developing fetal or infant brain. The motor disorders of CP are often accompanied by of sensation. disturbances cognition. communication, perception, and/or behaviour, and/or by a seizure disorder.1 There is no doubt that the incidence in the third world is much higher and that potentially preventable causes, especially perinatal ones, are more common in developing countries.2 There are a few prevalance studies of the CP population in Turkey. In one recent study; Serdaroglu et al have showed that the prevalance rate of CP was 4.4 per 1000 in Turkey and has been comparably higher than that reported for other developed and developing countries.3 High prevalance rates of CP bring about the need for current studies on children with CP as well as more global frameworks to create the common language and to perform a bridge between health professionals and families of children with CP in Turkey.

The World Health Organization (WHO) is encouraging application of International Classification of Functioning, Disability and Health (ICF); as a classification tool and also as a framework for social policy, research, education, and clinical practice. The approach to the assessment and management of children and youth with CP may depend to a considerable extent on frameworks used to conceptualize diseases and disorders.4-6 ICF has two parts, each with two components. Part I, Functioning and Disability, includes body functions, structures and activities and participation while Part II, Contextual Factors, includes environmental and personal factors. Each component of parts can be expressed in both positive and negative terms. "Disability" is used as the negative aspect of functioning including "impairment, activity limitation at the level of an individual and participation restriction at the level of society".4 In the chinical context of pediatric neurorehabilitation, appropriate and accurate tools are essential to measure the most relevant outcomes for activity limitations and participation restrictions.7 The ICF model of functioning and

disability provides many more "points of entry" for people seeking both to enhance the activity and participation of children whose functionality is at risk and to prevent secondary impairments. There is still little practical experience in the use of these classifications in the pediatric population, because until recently they have mostly been tested on adults 9-12

Rosenbaum and Stewart pointed out that researchers and educators also have a professional responsibility to study the application of this new model, and to provide critical feedback to the WHO.⁶ If we start out from that point, this ICF study is the preliminary experience in cerebral palsy from Turkey.

The aim of this study was to analyze and to investigate the correlation between the preliminary clinical experience of functioning and disability in the aspect of impairment, activity limitation, and participation restriction in self care, mobility, communication, social relations, learning and applying knowledge as proposed in the ICF, and to examine the relation of ICF with functional independence in children with CP.

Materials and methods

Participants

The study included 83 children with various types and severity of CP. Participants were 40 girls and 43 boys, aged 5 to 12 years with a mean age of 7.45±2.51 years. The selection of participants were from the children who were diagnosed as "CP" and refered to Hacettepe University, Faculty of Health Sciences, Department of Physical Therapy and Rehabilitation, CP Unit for a home exercise programme and children of parents who had accepted to attend this study. Informed consent was taken from the families.

Procedure

Sources of information were direct observation of pediatric physical therapist, written reports of, health related professionals, teachers, families and some of the participating children with CP.

Clinical type and extremity distribution of children were determined according to definitions adopted for European Classification of CP in Surveillance of Cerebral Palsy in Europe (SCPE)¹³ as seen in Appendix I. We classified our participants according to SCPE as it is simple, pratical and clear for classification. We addressed "impairments" as spasticity, mental retardation, epilepsy, visuel, hearing, speech impairments and hydrocephalus and any others. Spasticity was assessed by pediatric physical therapists. We used a questionnaire for parents to detect IQ levels of their children because we had no possibility to obtain Verbal IQ results of children. Mental retardation was defined as, no mental retardation for IO>70, retarded for IO<70.

Activity limitations were studied with the Gross Motor Function Classification System (GMFCS), ¹⁴ and Bimanual Fine Motor Function (BFMF). ¹⁵ GMFCS is a five level ordinal grading system determining motor disability of children with CP. BFMF was developed with the aim of correspondence with the levels of the GMFCS for assessing upper extremity function in CP but has not been as extensively studied as the GMFCS.

Participation restriction was studied in self care, mobility, communication, social relations, learning and applying knowledge, and was assessed with a code, a five level ordinal qualifier to describe the extent and magnitude of the problem, between no problem-complete problem.

The WeeFIM instrument was used to detect the functional abilities of participants. It is a pediatric functional assessment tool to assess severity of disability and contains 18 measurement items that has motor and cognitive subscales. A 7 level ordinal rating system ranging from 7 (complete independence) to 1 (total assistance) is used to rate performance. 16

We studied associations and correlations between clinical type and extremity distribution, impairments, activity limitation and participation restriction in self care, mobility, communication, social relations, learning and applying knowledge, and the relation of ICF with functional independence in children with CP.

Statistical analysis:

Crosstabs were used for twoway and multiway tables, and ANOVA test were used to analyze the effects of explanatory variables on a dependent continuous variable. Spearman rank correlation test was used to analyze the relation between various parameters, and p values of both <0.01 and <0.05 are considered statistically significant.

Results

The distribution of impairments by subtypes of CP according to SCPE is given in Appendix I. All children had at least one impairment. Bilateral spastic type of CP made up 81.6% of the total impairments. Unilateral spastic type had 13.8%, ataxic had 0.4%, dystonic had 2.4% and coreathetoid had 1.4% of total impairments. Spasticity occured in 93.7% of the children, mental retardation in 50.6%, epilepsy in 22.8%, visuel problems in 19.2%, hearing in 44.5%, speech problems in 7.2% and hydrocephalus in 4.8% of the children.

The association between activity limitations in gross and fine motor function by subtypes of CP as GMFCS and BFMF are also shown in Table 1. The GMFCS was at Level I in 26.5% of the children, at Level II in 16.8%, at Level III in 22.8%, at Level IV in 15.6% and at Level V in 18%. The BFMF was at Level I in 28.9% of the children, at Level II in 34.9%, at Level III in 9.6%, at Level IV in 18% and at Level V in 8.4%.

Participation restrictions by activity limitations according to GMFCS and BFMF are shown in Table 2. The restriction in self care was considered none in 9.6%, mild in 18%, 19.2% moderate, 31.3% severe, 21.6% complete. Levels I and II were considered as mild, Level III as moderate, Level IV as severe and Level V as complete restriction in GMFCS and BFMF. Proportions for levels of GMFCS were 42.1%, 22.9%, 16.9% and 18.1% respectively and for levels of BFMF 65%, 9.6%, 16.9% and 8.4% respectively. The restriction in mobility was considered as; none in 12%, mild in 22.8%, moderate in 16.8%, severe in 32.5%, complete in of children, the restriction communication as; none in 32.8%, mild in 21.6%, moderate in 22.8%, severe in 13.2%, complete in 12% of children, the restriction in social relations as; none in 13.2%, mild in 33.7%, moderate in 174 Kerem Günel

24%, severe in 14.4%, complete in 14.4% of children. The restriction in learning and applying knowledge was considered as none in 18%, mild in 21.6%, moderate in 24%, severe in 18%, complete in 18% of children.

Spearman rank correlation between impairments, activity limitations, participation restriction and total score of WeeFIM are shown in Table 3. Correlations between speech and mental retardation, and epilepsy and hearing were highly significant (p<0.01) as well as mental retardation and epilepsy, hearing and visuel impairments had significant correlation (p<0.01). There was a strong correlation of 0.82 between GMFCS and BFMF (p<0.01). In addition, GMFCS correlated with mental retardation, hearing and speech, while BFMF had a correlation with mental retardation (p<0.01).

All of the participation restriction parameters; learning and applying knowledge, mobility, communication, selfcare, social relations and WeeFIM total score had significant correlation between mental retardation, epilepsy, speech, GMFCS and BFMF. All correlations were significant at p<0.01 level and are shown in Table 3.

Discussion

This study investigated functioning and disability from the aspect of impairment, activity limitation and participation restriction as proposed in the ICF and their relation with functional independence in children with CP. It is evident that there is need for these ICF studies in the pediatric population. 15,17 Childhood disability peculiar features because of developmentally related changes that interact, modulate and are influenced by chronic health conditions. Furthermore children experience complex disability more often than adults involving multiple functions and activities.17

The traditional clinical terminology used to describe the subtypes of CP has been confusing. 18 and the standard form for describing children with a central motor deficit is an attempt to avoid these terms. 19 In this study, clinical type and extremity distribution, subtypes of CP were determined by SCPE. We trained ourselves by means of the SCPE manuel CD before classifying the children.20 SCPE has provided a unique opportunity for a number of diciplines in different CP registers to achieve a consensus of issues definition classification.13 Gorter et al pointed out that elegant work of SCPE, leaves open judgement how distinguish with precision unilateral from bilateral CP as well as how to distinguish diplegia from quadriplegia.21 In our opinion, SCPE for subtypes of CP is a simple, pratical, and clear classification.

All cases had impairments, spasticity, mental retardation, epilepsy were frequent with 93.7%, 50.6%, and 22.8% proportions respectively. In Beckung study, mental retardation and epilepsy were most frequent, with 40% and 35%, respectively. These results are compatible with

Table 1. Activity limitations according to subtypes of cerebral palsy (N=83).

	Gross Motor Function Classification levels						Bimanuel Fine Motor Function levels					
	1	2	3	4	5	1	2	3	4	5		
	n	n	n	n	n	n	n	n	n	n		
Bilateral spastic (N=63)	7	12	18	12	14	19	18	7	12	7		
Unilateral spastic (N=15)	14	-	1	-	-	5	9	1	-	-		
Ataxic (N=1)	1	,2	-	*	-	-	1	-	-	-		
Dystonic (N=2)	-	~	-	1	1	-	1	9#0	1	_		
Choreathetotic (N=2)	-	2	2		-	-	-	-	2	-		
Total	22	14	19	13	15	24	29	8	15	7		

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Table 2. Participation restrictions by activity limitations in children with cerebral palsy.

	Gross Motor Function Classification levels					Bimanuel Fine Motor Function levels					
	1	2	3	4	5	1	2	3	4	5	
	n	n	n	n	n	n	n	n	n	n	
Self care						7	1		÷	-	
None (n=8)	8	-		-	-	8	7	15	5		
Mild (n=15)	10	5	-	-	-	6	9	1	-		
Moderate (n=16)	3	5	7	1	E	4	12	6	4	-	
Severe (n=26)	1	3	11	9	2	-	2	1	10	7	
Complete (n=18)	-	-	1	4	13						
Mobility						7	3	-	-	-	
None (n=10)	10		-	-		10	9	-	-	-	
Mild (n=19)	11	8	~	-		6	7	-		1	
Moderate (n=14)	1	3	9	1	-	2	10	8	7	12	
Severe (n=27)	-	2	10	12	3	-	-	-	6	7	
Complete (n=13)	-	-	5 0	1	12						
Communication						15	7	1	2	-	
None (n=25)	13	5	4	3	4	8	9	1	ü	**	
Mild (n=18)	8	7	3		w	1	10	5	2	1	
Moderate (n=19)	1	-	11	5	2	1	3	1	6	-	
Severe (n=11)	-	1	1	5	4	-	-	72	4	6	
Complete (n=10)	-	-	-	1	9						
Social relations						8	2	-	1	-	
None (n=11)	8	1	1	1	8	12	13	2	1	2	
Mild (n=28)	9	11	6	2	ë	3	11	4	1	1	
Moderate (n=20)	4	(7)	11	3	2	1	3	2	6	-	
Severe (n=12)	1		1	7	3	1	-	-	5	6	
Complete (n=12)	-	1	-	1	10						
Learning						11	3	4	1	12	
None (n=15)	11	3		1	+	5	11	1	1	-	
Mild (n=18)	6	6	4	2	¥	6	10	3	4	1	
Moderate (n=20)	5	2	11	1	1	3	3	3	6		
Severe (n=15)	-	2	3	7	3	120	2	1	6	6	
Complete (n=15)		-	1	3	11						
Total	22	13	19	14	15	25	29	8	14	7	

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Table 3. Correlations between impairments, activity limitations, participation restriction and functional independence.

	MR	GMFCS	BMFM	LAK	Comm	Mobility	Selfcare	Social R	WeeFIM
	r	r	r	r	r	r	r	r	r
MR	[4]								1377.
GMFCS	0.54*	25							
BFMF	0.44*	0.82*							
LAK	0.81*	0.76*	0.64*						
Comm	0.80*	0.73*	0.68*	0.88*	-				
Mobility	0.57*	0.90*	0.77*	0.79*	0.78*	(4)			
Selfcare	0.59*	0.86*	0.78*	0.79*	0.77*	0.88*	Ψ.		
Social R	0.79*	0.70*	0.66*	0.84*	0.90*	0.74*	0.72*	-	
WeeFIM	-0.68*	0.90*	0.81*	-0.83*	-0.85*	-0.90*	-0.88*	-0.81*	-

BFMF: Bimanuel Fine Motor Function, Social R: Social relations.

each other and Hagberg et al and Nordmark et al studies. 22-24 Beckung and Hagberg found that impairments were associated with type of CP.15 Our results showed that bilateral spastic CP had major and higher impairment than unilateral spastic type, which coincides with the Beckung's study. One of the limitations of our study was not being able to compare ataxic and dyskinetic type of CP with spastic CP as we had only a few number of cases in these groups.

For classification of gross motor function, the GMFCS was used. The GMFCS was at Level I in 26.5% at Level II in 16.8%, at Level III in 22.8%, at Level IV in 15.6% and at Level V in 18%. The distribution was similiar to the Canadian report of 586 children with CP, where 28% of children were in Level I, 13% in level II, 19% in level III, 21% in Level IV and 19% in Level V.14

Beckung and Hagberg developed a 5 point bimanuel classification system from Krageloh-Mann and colleagues' study to correspond with GMFCS. 15,25 From our point of view, upper extremity of children with CP required a clinical classification to interpret upper extremity function, evaluation, and effectiveness of treatment, BFMF meets and fits this requirement. The correlation between GMFCS and BFMF was strong as similar to Beckung et al study showing that gross and fine motor functions were paralel.

Activity limitations are difficulties that an individiual may have in executing activities and participation restrictions are problems individual may experience during life situations. Activity limitations and participation restriction form negative aspect of ICF functioning and disability are very closely related with functional independence in daily living activities. It is always important to interpret function as an outcome in treatment in children with CP. Battagila et al found statistically highly significant correlation between WeeFIM, GMFCS and ICF activity participation domanins.¹⁷ We used WeeFIM, as an outcome measure of functional independence and investigated effects of participation of restriction on functional independence. We found statistically significant effects of participation restriction on WeeFIM subtypes and WeeFIM total score.

In conclusion, our preliminary experience indicated that ICF is a useful classification tool as well as reflects clinical functionality of children with CP. We think that ICF can be an appropriate model for our country if a common language in the rehabilitation team of children with CP may be provided, and if its use becomes widespread around Turkey.

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Appendix. Definitions adopted for European Classification of Cerebral Palsy (CP).

Spastic CP is characterized by at least two of the following:

Abnormal posture and/or movement

Increased tone (not necessarily constant)

Pathological reflexes (increase in reflexes: hyperreflexia and/or pyramidal signs, e.g, Babinski response)

Spastic CP may be either bilateral or unilateral

Spastic bilateral CP is diagnosed if:

Limbs on both sides of the body are involved

Spastic unilateral CP is diagnosed if:

Limbs on one side of the body are involved

Ataxic CP is characterized by both of the following:

Abnormal posture and/or movement

Loss of orderly muscular coordination so that movements are performed with abnormal force, rhythm, and accuracy

Dyskinetic CP is dominated by both of the following:

Abnormal posture and/or movement

Involuntary, uncontrolled, recurring, occasionally stereotyped movements

Dyskinetic CP may be either dystonic or choreo-athetotic:

Dystonic CP is dominated by both:

Hypokinesia (reduced activity, i.e. stiff movement)

Hypertonia (tone usually increased)

Chorea-athetotic CP is dominated by both

Hyperkinesia (increased activity, i.e. stormy movement)

Hypotonia (tone usually decreased)