# PETERSON MARCO DE OLIVEIRA ANDRADE

# AVALIAÇÃO DA FUNCIONALIDADE EM CRIANCAS COM DISFUNÇÕES NEUROLÓGICAS USANDO A CLASSIFICAÇÃO INTERNACIONAL DE FUNCIONALIDADE, INCAPACIDADE E SAÚDE (CIF) COMO REFERÊNCIA

Belo Horizonte 2012

### PETERSON MARCO DE OLIVEIRA ANDRADE

# AVALIAÇÃO DA FUNCIONALIDADE EM CRIANCAS COM DISFUNÇÕES NEUROLÓGICAS USANDO A CLASSIFICAÇÃO INTERNACIONAL DE FUNCIONALIDADE, INCAPACIDADE E SAÚDE (CIF) COMO REFERÊNCIA

Tese apresentada ao Programa de Pós-Graduação em Neurociências do Instituto de Ciências Biológicas da Universidade Federal de Minas Gerais, como requisito para obtenção do título de Doutor em Neurociências.

Área de concentração: Neurociências Clínica.

**Orientador: Prof. Dr. Vitor Geraldi Haase.** Universidade Federal de Minas Gerais

Belo Horizonte 2012

Andrade, Peterson Marco de Oliveira.

Avaliação da funcionalidade em crianças com disfunções neurológicas usando a Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) como referência. [manuscrito] / Peterson Marco de Oliveira Andrade. – 2012.

155 f. : il.; 29,5 cm.

Orientador: Vitor Geraldi Haase.

Tese (doutorado) – Universidade Federal de Minas Gerais, Instituto de Ciências Biológicas.

1. Manifestações neurológicas de doenças – Teses. 2. Reabilitação – Teses. 3. Paralisia cerebral - Teses. 4. Organização Mundial da Saúde – Teses. 5. Neurociências – Teses. 6. Sistema nervoso – Doenças – Teses. 7. Classificação Internacional de Funcionalidade, Incapacidade e Saúde. I. Haase, Vitor Geraldi. II. Universidade Federal de Minas Gerais. Instituto de Ciências Biológicas. III. Título.

CDU: 616.83



UNIVERSIDADE FEDERAL DE MINAS GERAIS PROGRAMA DE PÓS-GRADUAÇÃO EM NEUROCIÊNCIAS www.ufmg.br/neurociencias

"Avaliação da funcionalidade em crianças com disfunções neurológicas usando a Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) como referência"

Aluno: Peterson Marco de Oliveira Andrade

Tese defendida em 12/03/2012.

Resultado:

Banca Examinadora constituída pelos seguintes professores:

Prof. Dr. Vitor Geraldi Haase UFMG (orientador)

USMAM

Prof. Dra. Cássia Maria Buchalla USP

Prof. Dr. John Henry Stone University at Buffalo

Cesmon May and Profa. Dra. Leonor Bezerra

UFMG

Profa. Dra. Livia Magalhães UFMG

Programa de Pós-graduação em Nearocências Av. Antônio Carlos, 6027 ICB sala Bioco F1 298 ( Pampulha) Reio Horizonte ( MG ) Brasil CEP 31276-901-Telefax ++ 55 31 3409 2546 neurociencias@iob.atmg br

### AGRADECIMENTOS

Ao **Prof. Vitor Geraldi Haase**, por ter acreditado e apoiado a minha proposta de doutorado.

Ao **Programa de Pós Graduação em Neurociências da UFMG**, pelo incentivo permanente pela qualidade e produção científica.

A Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (CAPES) pelo apoio financeiro.

Aos membros da banca de qualificação, **Prof. Arthur Kummer (UFMG), Profa.** Lívia Magalhães (UFMG) e Shamyr Castro (UFTM), pela análise crítica do trabalho e contribuições para a versão para a defesa.

Aos membros da banca de defesa, Profa. Cássia Buchalla (USP), Prof. John Stone (University at Buffalo) Profa. Leonor Bezerra (UFMG) e Profa. Lívia Magalhães (UFMG) pela análise crítica do trabalho e contribuições para a versão final desta tese.

Aos **pais e crianças que participaram deste estudo**, sem a presença de vocês este trabalho não seria possível.

A minha esposa, Fernanda Ferreira, pelo apoio, parceria, colaboração e paciência.

A **minha mãe, Mirly Cecílio de Oliveira**, pelo apoio e incentivo educacional durante minha graduação e pós- graduações.

Ao **meu pai, Paulo Moisés de Oliveira Andrade**, pelo exemplo de superação dos limites físicos.

A minha família, pela compreensão das minhas ausências e apoio.

Aos meus mestres pelos ensinamentos, críticas construtivas e pelo exemplo a ser seguido.

Aos alunos de iniciação científica da Universidade Federal dos Vales do

Jequitinhonha e Mucuri, pela dedicação e compromisso para o desenvolvimento da ciência.

Aos meus amigos, pela amizade, paciência com minhas ausências e apoio

### DEDICO ESSE TRABALHO A VOCÊS!

## RESUMO

**Introdução:** A operacionalização da perspectiva biopsicossocial preconizada pela OMS apresenta dificuldades teóricas e metodológicas devido a complexidade da Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF). A paralisia cerebral (PC) pode desencadear deficiências nas estruturas e funções do corpo, limitações nas atividades e restrição de participação. Os fatores contextuais atuam como barreiras ou facilitadores para o desempenho e capacidade de crianças com PC. Desta forma, o modelo multidimensional da CIF pode ser usado para a investigação da funcionalidade desta condição. Considerando a CIF, algumas questões desafiam a operacionalização da perspectiva biopsicossocial: 1) Quais categorias da CIF devem compor uma avaliação abrangente da PC por uma equipe de reabilitação? 2) Quais itens são documentados nos prontuários? 3) Os profissionais conhecem o modelo da CIF? 4) Os conceitos da CIF são de fácil operacionalização? 5) Qual é o perfil funcional e contextual de crianças com disfunções neurológicas? Diante destas questões, o objetivo geral da presente tese foi aplicar o modelo da CIF com diferentes finalidades com a proposta de iniciar um debate sobre o uso desta classificação para avaliação e reabilitação de crianças com disfunções neurológicas. Métodos: Foram desenvolvidos cinco estudos (dois estudos empíricos, um estudo de análise de prontuários de um Núcleo de Reabilitação, um painel de *experts* e uma revisão crítica da literatura) com o objetivo de responder às questões da tese. Resultados: Um conjunto de categorias da CIF relevantes para a avaliação da PC foi levantado através da percepção dos profissionais envolvidos com a reabilitação da PC e através da análise de prontuários. Deficiências nas funções do corpo, limitações nas atividades e influência dos fatores ambientais na funcionalidade dos casos de PC foram avaliados pelos estudos empíricos desenvolvidos. Questões relacionadas com o construto de capacidade da CIF foram levantadas e discutidas em um estudo de revisão com o objetivo de iniciar um debate sobre os métodos aplicados para investigação do componente de atividade e participação. Considerações Finais: A operacionalização da perspectiva biopsicossocial exige a articulação de diferentes métodos teóricos e empíricos. A PC apresenta-se com um quadro funcional heterogêneo, pois existem diferentes comprometimentos nas funções cognitivas e motoras. Os fatores ambientais devem ser considerados nas avaliações das equipes de reabilitação, pois atuam como facilitadores ou barreiras para a funcionalidade dos casos. Avanços conceituais e metodológicos são necessários para a efetivação da proposta da OMS.

## ABSTRACT

Introduction: The operationalization of the biopsychosocial approach recommended by WHO presents theoretical and methodological difficulties due to the complexity of the International Classification of Functioning, Disability and Health (ICF). Cerebral palsy (CP) can trigger impairments in structures and body functions, limitations in activities and participation restrictions. Contextual factors may influence as barriers or facilitators to the performance and capacity of children with CP. Thus, the multidimensional model of the ICF can be used to investigate the functioning of this disease. Considering the ICF, some issues may arise for the operationalization of the biopsychosocial perspective: 1) What categories of ICF should comprise a CP assessment by a rehabilitation team? 2) What items are documented in the records? 3) Do the professionals know the ICF model? 4) Are the concepts of the ICF easily managed? 5) What is the functional and contextual profile of children with neurological disorders? Given these issues, the goal of this thesis was to apply the ICF model with different purposes with the aim to initiate a debate on the use of this classification by health professionals in children with neurological disorders. Methods: Five studies were developed (two empirical studies, a records analysis of a Rehabilitation Center, a panel of experts and a literature review). Results: An ICF code sets for the evaluation of CP has been raised through the perceptions of professionals involved with the rehabilitation of the CP and through analysis of medical records. Impairments in the body functions, limitations in activities and influence of environmental factors on the functioning of CP were observed by empirical study. Issues related to the capacity of the ICF construct were performed in order to start a discussion about the methods used to investigate the activity and participation component. Final Considerations: The operationalization of the biopsychosocial approach requires the articulation of different theoretical and empirical methods. The CP is presented with a heterogeneous functional profile, since there are different impairments in cognitive and motor functions. Environmental factors should be considered in the evaluations of the rehabilitation team, because they act as facilitators or barriers to the functioning of the cases. Conceptual and methodological advances are needed to accomplish the WHO purpose.

# LISTA DE ILUSTRAÇÕES

# ESTUDO 2

FIGURE 1 - Flow of the methods employed	.53
ESTUDO 3	
FIGURE 1 - Study steps	.97
ESTUDO 4	
FIGURE 1 - Article Selection Flow	124

# LISTA DE TABELAS

### **ESTUDO 1**

TABELA 1- C	Caracaterísticas sócio-demográficas e grau de comprometimento motor
do	os participantes separados por grupo32
TABELA 2- A	Análise descritiva e comparativa (ANOVA) das respostas à checklist
ba	aseada na CIF e desempenho no MEEM dos três grupos participantes
(C	controles, PC, AVC)
TABELA 3- P	Perfil dos conglomerados formados com relação ao escore no MEEM, s
fa	acilitadores ambientais específicos, e comprometimento motor
TABELA 4- C	Características clínicas e sócio-demográficas dos conglomerados
fo	ormados

### ESTUDO 2

TABLE 1-	Example of the linking process between the information contained in	
	medical records and the ICF-CY	55

TABLE 4-	Items described in the records of cases of hemiplegic CP73
TABLE 5-	Items described in the records of cases of diplegic cerebral palsy74
TABLE 6-	Items described in the records of cases of quadriplegic CP75
TABLE 7-	Categories that presented a minimum frequency of 40% during the registration process for HCP, DCP or QCP76
ESTUDO 3	3
TABLE 1-	Characteristics of the Center for Rehabilitation professionals
TABLE 2-	ICF knowledge, training program and a consensus for CP evaluation - self-reported
TABLE 3-	Number of ICF codes reported by professionals through use of a semi- structured questionnaire
TABLE 4-	Number of ICF items selected by professionals through structured questionnaire
TABLE 5-	ICF categories described (Questionnaire I) and ICF codes selected (Questionnaire II). by professionals for CP functioning evaluation and codes for screening in a rehabilitation service (PHY = physician, PT = physical therapist, ST = speech therapist, OT = occupational therapist, PSY = psychologists, SW= social workers, NT= nutrition , DT = dentistry)

# ESTUDO 4

TABLE 1	Concepts of capacity, capability, and performance defined by the WHO and by Holsbeeke et al
TABLE 2	- Type and number of studies105
TABLE 3	- Empirical studies that used the terms capacity, capability, or performance in the abstract
TABLE 4	Instruments related to the use of the term capacity
TABLE 5	<ul> <li>Proposal of a definition of functional capacity and potential performance as well as the contextual factors involved in these constructs115</li> </ul>
ESTUDO	5
TABLE 1	<ul> <li>ICF categories assessed by the Mini-Mental State Examination130</li> </ul>
TABLE 2	- Characteristics of CP cases and results of the instruments for each subgroup
TABLE 3	- Socioeconomic status according to the motor impairment
TABLE 4	Difficulties in activities according to the motor impairment
TABLE 5	- Barriers for functioning related by parents
TABLE 6	- Regression Analysis140

# LISTA DE ABREVIATURAS E SIGLAS

ABEP	Associação Brasileira de Empresas de Pesquisa							
AFARNI	Avaliação dos fatores ambientais relacionados à reabilitação							
	Neurológica Infantil							
APAE	Associação dos Pais e Amigos dos Excepcionais							
ANOVA	Analysis of variance							
AVC	Acidente Vascular Cerebral							
BEF	Basic Environmental Factors							
CCEB	Critério de Classificação Econômica Brasil							
CGP	Centro Geral de Pediatria							
CID	Classificação Estatística Internacional de Doenças e Problemas							
	Relacionados à Saúde							
СР	Cerebral Palsy							
CIF	Classificação Internacional de Funcionalidade, Incapacidade e Saúde							
DCP	Diplegic Cerebral Palsy							
DF	Degrees Freedom							
DT	Dieticians							
FHEMIG	Fundação Hospitalar do Estado de Minas Gerais							
GMFCS	Gross Motor Classification System							
GMFM	Gross Motor Function Measure							
HCP	Hemiplegic Cerebral Palsy							
HDI	Human Developmental Index							
IBACP	ICF-based approach for Cerebral Palsy							
IBI-CP	ICF-based instrument for cerebral palsy							
IMPACT-S	ICF Measure of Participation and ACTivities							
ICF	International Classification of Functioning, Disability and Health							
ICF-CY	International Classification of Functioning, Disability and Health for							
	Children and Youth							
ICIDH	International Classification of Impairments, Disability and Handicap							
LND	Laboratório de Neuropsicologia do Desenvolvimento							
MACS	Manual Ability Classification System							
MEEM	Mini-exame do Estado Mental							

MMSE	Mini-Mental State Examination
MUUL	Melbourne Unilateral Upper Limb Assessment of function
OD	Odds Ratio
OMS	Organização Mundial de Saúde
OT	Occupational Therapy
PC	Paralisia Cerebral
PHY	Physician
PSY	Psychologist
PT	Physical Therapy
ROC	Receiver-operating characteristic curves
SD	Standard Deviation
SEF	Specific Environmental Factors
SES	Socioeconomic Status
SES-MG	Secretaria Estadual de Saúde de Minas Gerais
SPSS	Statistical Package for Social Science
ST	Speech Therapy
SW	Social Worker
QCP	Quadriplegic Cerebral Palsy
WHO	World Health Organization

# **SUMÁRIO**

1	INTRODUÇÃO	16
2	OBJETIVOS	. 23
2.1	OBJETIVO GERAL	. 23
2.2	OBJETIVOS ESPECÍFICOS	. 23
3	MATERIAIS E MÉTODOS	25
4	RESULTADOS	27
4.1	ESTUDO 1: PERFIL COGNITIVO, DÉFICITS MOTORES E	
INFL	JÊNCIA DOS FACILITADORES PARA REABILITAÇÃO PAR	Α
CRIA	NÇAS COM DISFUNÇÕES NEUROLÓGICAS	27
12		
INIE		
	RDISCIPLINARY ASSESSMENT OF CEREBRAL PALSY USI	NG
THEI	RDISCIPLINARY ASSESSMENT OF CEREBRAL PALSY USI NTERNATIONAL CLASSIFICATION OF FUNCTIONING,	NG
THE I	RDISCIPLINARY ASSESSMENT OF CEREBRAL PALSY USI NTERNATIONAL CLASSIFICATION OF FUNCTIONING, BILITY AND HEALTH AS REFERENCE	<b>NG</b> 48

4.3 ESTUDO 3: MULTIDISCIPLINARY PERSPECTIVE FOR CEREBRAL PALSY ASSESSMENT AFTER AN INTERNATIONAL, CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH 

4.4 ESTUDO 4: IS THE CAPACITY CONSTRUCT FROM INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH USED IN EMPIRICAL STUDIES OF CEREBRAL PALSY?

# 1 INTRODUÇÃO

A Organização Mundial de Saúde (OMS) recomenda, no "World Report on Disability", (WHO, 2011) o uso da estrutura e modelo da Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) para avaliação da funcionalidade das pessoas com deficiências nas estruturas e funções do corpo. A paralisia cerebral (PC) e o acidente vascular cerebral (AVC) em crianças ou adolescentes podem promover um quadro clínico heterogêneo com diferentes comprometimentos cognitivos e motores (Beckung & Hagberg, 2002, Gordon et al, 2002). O efeito destes comprometimentos nas capacidades e no desempenho das crianças com disfunções neurológicas depende das interações das deficiências com os fatores contextuais em que a criança está inserida. A maioria dos estudos relacionados com a PC ou AVC na infância abordam os aspectos biomédicos de investigação da etiologia das doenças ou na avaliação de efeitos de tratamentos nas estruturas e funções do corpo (Kirkhan et al, 2004, Barreirinho et al, 2003). Estudos dos aspectos biopsicossociais que envolvem a saúde de crianças com disfunções neurológicas são escassos. Pesquisas são necessárias para desenvolver instrumentos de avaliação conforme as recomendações da OMS (OMS, 2003).

A CIF foi aprovada pela 54ª Assembléia de Saúde da OMS, em maio de 2001, e apresenta como objetivo: padronizar a terminologia dos aspectos da saúde e relacionados com a saúde. Além disso, esta classificação apresenta um modelo multidimensional relacionado com o processo de funcionalidade, incapacidade e saúde (WHO, 2001). Os componentes da CIF (estruturas e funções do corpo, atividade e participação, fatores ambientais e fatores pessoais) interagem através de alças de retroalimentação. As categorias da CIF são organizadas por meio de um sistema hierárquico e apresenta 30 capítulos (8 de funções do corpo, 8 de estruturas de corpo, 9 de atividade e participação e 5 de fatores ambientais). Cada capítulo apresenta subcategorias de segundo, terceiro e até quarto nível para discriminação dos itens. A CIF apresenta 362 categorias de segundo e até 1424 categorias de terceiro e quarto nível (OMS, 2003). O relatório mundial sobre a deficiência (WHO, 2011) apresenta informações e recomendações para os cuidados de saúde e

estratégias de educação para pessoas com problemas nas estruturas e funções do corpo.

A CIF pode ser utilizada na área de neurociências, pois apresenta capítulos relacionados com as estruturas do sistema nervoso, funções mentais, funções sensoriais e funções neuromusculoesqueléticas (OMS, 2003). Pesquisadores de Institutos ou Departamentos de Neurociências de países como a Suécia (Haglund & Henriksson, 2003; Daremo & Haglund, 2008), Dinamarca (Biering-Sorensen, et al. 2006), Espanha (Vieta et al, 2007), Holanda (Post et al, 2010) e Bélgica (Bouffioulx, Arnould, Thonnard, 2011; Bollens et al, 2011) utlizaram o modelo da CIF em suas publicações. A Neurociência Clínica pode utilizar o modelo biopsicossocial para orientar o raciocínio clínico e a formulação de pesquisas em casos de doenças neurológicas e psiguiátricas. A "constraint-induced movement therapy" é, por exemplo, uma estratégia ambiental que apresenta o objetivo de estimular as funções neuromusculoesqueléticas através de atividades desenvolvidas na rotina do indivíduo, como ações de cuidado pessoal e vida doméstica. Este é um exemplo de plasticidade sináptica dependente de atividade (Hebb, 1949). Outros esforços da neurociência estão relacionados com as interfaces cérebro-máquina (relação entre uma estrutura do corpo e um fator ambiental facilitador para realização de atividades) (Nicolelis & Lebedev, 2009). Desta forma, o estudo de interações entre os componentes da CIF representa um dos esforços das pesquisas relacionadas com as neurociências.

Considerando a abrangência biopsicossocial da CIF, o número de subcategorias e as interações entre os seus componentes, esta classificação é considerada complexa, e por isso, pouco utlizada na prática clínica dos profissionais de saúde (Farias & Buchala, 2005). A pouca utlização também pode ser justificada pela carência de treinamentos sobre a CIF para os profissionais dos serviços de reabilitação (Andrade, Ferreira, Haase, 2011). Outro motivo pode estar relacionado com a complexidade de interpretação e operacionalização de alguns construtos da CIF como o de capacidade e desempenho (Andrade, Ferreira, Haase, submetido). Por isso, um amplo debate conceitual é necessário para facilitar o uso empírico da CIF.

A literatura relacionada com o estudo da PC é mais focada na investigação dos aspectos motores. As relações entre os comprometimentos motores e os aspectos cognitivos e contextuais são negligenciadas (Pueyo *et al*, 2005, Bottcher, 2010). Além disso, as implicações destas relações nas capacidades ou desempenho são pouco investigadas. Esta lacuna está relacionada com a carência de instrumentos de avaliação com a cobertura biopsicossocial proposta pela CIF.

A maioria dos estudos que utilizaram a CIF como referências relacionam-se com a definição de um conjunto de categorias (códigos) para a avaliação de diferentes condições crônicas. Este conjunto de códigos é mais conhecido como ICF core sets. O desenvolvimento destes core sets são coordenados pelo ICF Research Branch da Universidade de Munique. Para aplicação na área de neurologia ou neuro-psquiatria existem core sets para depressão (Cieza et al., 2004), lesão medular (Biering-Sorensen et al., 2006), esclerose múltipla (Coenem et al, 2011), transtorno bipolar (Vieta et al, 2007), distúrbios do sono (Gradinger et al, 2011), doenças neurológicas agudas (Grill et al, 2005), entre outras. Para a PC e AVC infantil não há core sets. Existem core sets resumidos e ampliados. Os core sets ampliados devem ser utilizados por uma equipe multidisciplinar, enquanto a classificação nuclear resumida deve ser introduzida na prática clínica por um profissional de qualquer formação na área da saúde (Cieza et al, 2004). Os core sets definem o que deve ser avaliado e não como será operacionalizada a avaliação. Por isso, a partir da definição das categorias para mensuração da funcionalidade é preciso desenvolver instrumentos para operacionalizar o processo de avaliação.

Os esforços para o desenvolvimento de instrumentos baseados na CIF são incipientes e necessários para uma efetiva implantação de uma avaliação abrangente conforme proposto pela CIF, e ao mesmo tempo viável para ser aplicada em serviços públicos de reabilitação (Andrade & Haase, 2008). A Política Nacional de Saúde da Pessoa com Deficiência descreve os potenciais avanços que o uso da CIF pode promover para os serviços de reabilitação, para a elaboração de sistemas de informações em saúde, para a gestão da saúde pública e para a elaboração de políticas públicas (Ministério da Saúde, 2009). Por outro lado, não há evidências sobre o uso da CIF em serviços de reabilitação do Brasil ou sobre o treinamento dos profissionais de saúde sobre esta classificação. A perspectiva

biopsicossocial da CIF está em consonância com o Plano Nacional dos Direitos da Pessoa com deficiência conhecido como "Viver sem Limite" coordenado pela Secretaria de Direitos Humanos do Governo do Brasil, pois este plano envolve aspectos relacionados com as áreas de educação, atenção à saúde, acessibilidade e inclusão social (Brasil, 2011).

O uso da CIF durante o processo de reabilitação, o treinamento dos profissionais e o desenvolvimento de pesquisas sobre a deficiência são três das nove recomendações do *World Report on Disability* (WHO, 2011) que a presente tese procurou explorar. Pretende-se com esse trabalho contribuir para a fundamentação do uso desta classificação em crianças com disfunções neurológicas, tais como o AVC e a PC. Alguns aspectos metodológicos inovadores foram desenvolvidos a fim de tornar a avaliação funcional mais específica e organizada. Além disso, argumentos críticos foram abordados a fim de iniciar um debate sobre a necessidade de aprimoramento da CIF.

Os Estudos 1 e 5 foram pesquisas com crianças com diagnóstico de paralisia cerebral e/ou AVC na infância para investigar a funcionalidade de diferentes condições neurológicas e subtipos de paralisia cerebral (hemiplégica, diplégica e quadriplégica) de acordo com o modelo da CIF. Estes estudos apresentam o perfil funcional para diferentes quadros neurológicos e a necessidade de suporte para a reabilitação das crianças através de diferentes facilitadores.

O Estudo 2 avaliou o padrão de preenchimento dos prontuários de um serviço de reabilitação seguindo a CIF como referência. Este estudo é relevante para a observação dos registros de profissionais de sete áreas envolvidas com o processo de reabilitação (fisioterapia, nutrição, terapia ocupacional, medicina, fonoaudiologia, assistência social e odontologia).

Já o Estudo 3 apresenta o nível de conhecimento sobre a CIF dos profissionais envolvidos com o processo de reabilitação e o efeito de um treinamento sobre a CIF na aprendizagem dos profissionais participantes dos módulos da capacitação. Além disso, uma lista de itens da CIF para avaliação da funcionalidade da paralisia cerebral foi elaborada pelos profissionais participantes do treinamento.

Sabendo-se da necessidade de um debate crítico sobre as dificuldades de operacionalização da CIF na prática clínica, foi realizada uma revisão da literatura (Estudo 4) para apresentar evidências relacionadas com um dos pontos críticos da CIF: avaliar de forma consensual o componente de atividade da CIF.

Todos os estudos desenvolvidos estão relacionados com a questão da avaliação da funcionalidade de crianças com paralisia cerebral ou AVC, porém são independentes por apresentarem objetivos específicos distintos. Os resultados dos estudos podem contribuir para o planejamento e execução de ações educativas para os profissionais envolvidos com o processo de reabilitação das crianças com deficiências neurológicas.

Referências:

Andrade PMO, Ferreira FO, Haase VG. Multidisciplinary perspective for cerebral palsy assessment after an International, Classification of Functioning, Disability and Health training. Developmental Neurorehabilitation 2011;14(4):199-207.

Andrade, PMO, Haase, VG. Avaliação da funcionalidade em crianças e adolescentes com Paralisia Cerebral e Acidente Vascular Cerebral: um estudo exploratório. Dissertação de Mestrado apresentada no Programa de Pós Graduação em Ciências da Saúde: Área de Concentração em Saúde da Criança e do Adolescente da Universidade Federal de Minas Gerais; 2008.

Andrade PMO, Ferreira FO, Haase VG. Is the capacity construct from International Classification of Functioning, Disability and Health used in empirical studies of Cerebral Palsy? Submetido para Journal of Child Neurology. Artigo em revisão.

Barreirinho S, Ferro A, Santos M, Costa E, Pinto-Basto J, Sousa A, et al. Inherited and acquired risk factors and their combined effects in pediatric stroke. Pediatric Neurology. 2003; 28:134-8.

Beckung, E, Hagberg, G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Developmental Medicine Child Neurol* ogy 2002; 44: 309-16.

Biering-Sorensen, F. *et al.* Developing core sets for persons with spinal cord injuries based on the international classification of functioning, disability and health as away to specify functioning. Spinal Cord., v. 44, n. 9, p. 541-6, 2006.

Bollens B, Deltombe T, Detrembleur C, Gustin T, Stoquart G, Lejeune TM. Effects of selective tibial nerve neurotomy as a treatment for adults presenting with spastic

equinovarus foot: a systematic review. Journal of Rehabilitation Medicine. 2011 Mar;43(4):277-82.

Bottcher L. Children with spastic cerebral palsy, their cognitive functioning, and social participation: a review. Child Neuropsychology 2010; 16:209-28.

Bouffioulx E, Arnould C, Thonnard JL. Satisfaction with activity and participation and its relationships with body functions, activities, or environmental factors in stroke patients. Arch Phys Med Rehabil. 2011 Sep;92(9):1404-10.

Brasil. Secretaria de Direitos Humanos. Plano Nacional de Direitos das Pessoas com Deficiências (2011 – 2014). Viver sem limite. Acesso em 09/12/2011- Link: http://www.direitoshumanos.gov.br/destaques/campanha-viver-sem-limite.pdf Cieza A, Ewert T, Ustün TB, Chatterji S, Kostanjsek N, Stucki G.Development of ICF Core Sets for patients with chronic conditions. Journal of Rehabilitation Medicine. 2004 Jul;(44 Suppl):9-11.

Cieza A, Ewert T, Ustün TB, Chatterji S, Kostanjsek N, Stucki G. Development of ICF Core Sets for patients with chronic conditions. Journal of Rehabilitation Medicine. 2004; 44 Suppl:9-11.

Cieza, A. *et al.* ICF core sets for depression. Journal of Rehabilitation Medicine. Suppl. 44, p. 128-34, 2004.

Coenen M, Cieza A, Freeman J, Khan F, Miller D, Weise A, Kesselring J; The members of the Consensus Conference. The development of ICF Core Sets for multiple sclerosis: results of the International Consensus Conference. J Neurol. 2011 Aug; 258(8):1477-1488.

Daremo A, Haglund L. Activity and participation in psychiatric institutional care. Scand J Occup Ther. 2008 Sep;15(3):131-42.

Farias, N, Buchalla, CSA. Classificação internacional de funcionalidade, incapacidade e saúde da Organização Mundial da Saúde: conceitos, usos e perspectivas. Revista Brasielira de Epidemiologia., v. 8, p : 187-193 2005.

Gordon AL, Ganesan V, Towell A, Kirkham FJ. Functional outcome following stroke in children. Journal of Child Neurology. 2002; 17:429-34.

Geyh, S., Cieza, A., Schouten, J., Dickson, H., Frommelt, P., Omar, Z., Kostanjsek N., Ring, H., Stucki, G. ICF core sets for stroke. Journal of Rehabilitation Medicine. 2004; 44:135-41.

Gradinger F, Cieza A, Stucki A, Michel F, Bentley A, Oksenberg A, Rogers AE, Stucki G, Partinen M. Part 1. International Classification of Functioning, Disability and Health (ICF) Core Sets for persons with sleep disorders: results of the consensus process integrating evidence from preparatory studies. Sleep Medicine. 2011 Jan;12(1):92-6.

Grill E, Strobl R, Müller M, Quittan M, Kostanjsek N, Stucki G. ICF Core Sets for early post-acute rehabilitation facilities. Journal of Rehabilitation Medicine. 2011 Jan;43(2):131-8.

Haglund L, Henriksson C. Concepts in occupational therapy in relation to the ICF. Occup Ther Int. 2003;10(4):253-68.

Hebb, D. O. (1949), *The organization of behavior*, New York: Wiley.

Kirkham, FJ, Hogan, AM. Risk factors for arterial ischemic stroke in childhood. CNS Spectr. 2004; 9: 451-64.

Ministério da Saúde. Secretaria de Atenção à Saúde. Política Nacional de Saúde da Pessoa com Deficiência. Série E – Legislação em Saúde. 1 Edição. Brasília, 2009.

Nicolelis, M. A. & Lebedev, M. A. (2009). Principles of neural ensemble physiology underlying the operation of brain-machine interfaces. *Nature Reviews Neuroscience*, *10*, 530-540.

Organização Mundial de Saúde – OMS; Organização Panamericana de Saúde - OPAS. (2003). *Classificação internacional de funcionalidade, incapacidade e saúde*. São Paulo - SP: Universidade de São Paulo, 2003.

Post MW, Kirchberger I, Scheuringer M, Wollaars MM, Geyh S. Outcome parameters in spinal cord injury research: a systematic review using the International Classification of Functioning, Disability and Health (ICF) as a reference. Spinal Cord. 2010 Jul;48(7):522-8. 2010

Pueyo R, Junqué C, Vendrell P, Narberhaus A, Segarra D. Raven's Coloured Progressive Matrices as a measure of cognitive functioning in Cerebral Palsy. J Intellect Disabil Res. 2008 May;52(Pt 5):437-45. Epub 2008 Feb 28.

Vieta E, Cieza A, Stucki G, Chatterji S, Nieto M, Sánchez-Moreno J, Jaeger J, Grunze H, Ayuso-Mateos JL. Developing core sets for persons with bipolar disorder based on the International Classification of Functioning, Disability and Health. Bipolar Disorder. 2007 Feb-Mar;9(1-2):16-24.

World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.

World Health Organization. World Report on Disability. Geneva: WHO;2011.

## 2 OBJETIVOS

### 2.1 OBJETIVO GERAL

O objetivo geral do estudo foi aplicar o modelo da Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) da Organização Mundial de Saúde com diferentes finalidades com a proposta de iniciar um debate sobre o uso desta classificação para avaliação e reabilitação de crianças com disfunções neurológicas.

### 2.2 OBJETIVOS ESPECÍFICOS

Os objetivos específicos da tese são:

- a) Investigar se crianças e adolescentes saudáveis e com doenças neurológicas (paralisia cerebral, PC e sequela de acidente vascular cerebral, AVC) podem ser reunidas em grupos distintos e homogêneos usando como critérios o perfil cognitivo, o funcionamento motor e as percepções dos pais quanto aos facilitadores para a reabilitação.
- b) Identificar os itens relevantes e as mais freqüentes categorias (relacionadas com a funcionalidade e incapacidade) registradas por profissionais envolvidos com a reabilitação de crianças com paralisia cerebral.
- c) Avaliar o preenchimento dos prontuários de crianças com paralisia cerebral de um Núcleo de Reabilitação.
- d) Avaliar o conhecimento sobre a CIF de profissionais de reabilitação antes e depois de um treinamento sobre a CIF.
- e) Identificar itens para compor um conjunto de códigos para avaliação da paralisia cerebral em um Núcleo de Reabilitação.
- f) Identificar publicações que apresentaram a proposta de aplicar o construto de *capacity, capability* ou *performance* em casos de paralisia cerebral;
- g) Identificar os instrumentos utilizados no estudo da capacity;

- h) Discutir questões sobre o construto capacidade definido pela CIF e apresentar uma sugestão conceitual e metodológica para avaliação do desempenho potencial.
- i) Integrar instrumentos para avaliação das funções motoras e cognitivas, atividade e participação e fatores ambientais para a operacionalização de uma abordagem baseada na CIF
- j) Investigar a capacidade de um instrumento baseado na CIF para discriminar a funcionalidade de crianças com PC hemiplégica, diplégica e quadriplégica
- k) Investigar quais são as variáveis explicativas (cognitivas e/ou motoras) para a participação das crianças com paralisia cerebral em escolas regulares ou especiais.

# 3 MATERIAIS E MÉTODOS

Para a operacionalização dos objetivos foram realizados quatro estudos transversais e uma revisão estruturada da literatura. A Tabela 1 abaixo apresenta a relação entre os objetivos específicos da tese, os estudos desenvolvidos, as revistas científicas para as quais os estudos foram encaminhados e a situação atual do artigo.

Quadro 1 – Estudos desenvolvidos, objetivos específivos, revistas para as quais os artigos foram submetidos e situação dos artigos

Estudo	Objetivos	Revistas para submissão	Situação do artigo
	Específicos		
Estudo 1	а	Revista Paulista de Pediatria	Publicado <sup>1</sup>
Estudo 2	b, c, e	Disability and Rehabilitation	Publicado <sup>2</sup>
Estudo 3	d,e	Developmental Neurorehabilitation	Publicado <sup>3</sup>
Estudo 4	f,g,h	Journal of Child Neurology	Submetido e em revisão
Estudo 5	i,j,k	Physical and Occupational Therapy in	Submetido e em revisão
		Pediatrics	

Os artigos foram submetidos para periódicos indexados, pois uma publicação em periódico internacional é uma exigência mínima para a defesa da tese conforme o "Item 8.9.2" do Regulamento do Programa de Pós Graduação em Neurociências da Universidade Federal de Minas Gerais (UFMG)<sup>4</sup>.

Os materiais e métodos específicos empregados estão discriminados em cada estudo desenvolvido. O estudo 1 foi submetido para a Revista Paulista de Pediatria em português e o mesmo foi traduzido para a língua inglesa pela revista. Todos os artigos escritos na língua inglesa (Estudos 2 ao 5) foram revisados pelo *American Journal Experts*.

A formatação de cada estudo seguiu as normas específicas das revistas. As normas de cada periódico e o endereço eletrônico das revistas seguem na Tabela 2.

Quadro 2 – Revistas, normas para formatação dos estudos e endereço eletrônico dos periódicos.

Periódico	Normas do	Página (link) do periódico		
	periódico			
Revista Paulista de Pediatria	International Committee of Medical Journal Editors Uniform Requirements	http://www.scielo.br/scielo.php?scrip t=sci_serial&pid=0103-0582		
Disability and Rehabilitation	Council of Science Editors (CSE)	http://informahealthcare.com/dre		
Developmental Neurorehabilitation	Council of Science Editors (CSE)	http://informahealthcare.com/pdr		
Journal of Child Neurology	American Medical Association Manual of Style	http://jcn.sagepub.com/		
Physical and Occupational Therapy in Pediatrics	American Psychological Association Style	http://informahealthcare.com/loi/pop		

1- Andrade PMO, Ferreira FO, Vasconcelos AG, Lima EP, Haase VG. Cognitive profile, motor deficits and influence of facilitators for rehabilitation for children with neurological dysfunction. *Rev Paul Pedriatr* 2011; 29(3): 320-27.

2- Andrade PM, Oliveira Ferreira F, Mendonça AP, Haase VG. Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. *Disabil Rehabil*, 2012; (Epub ahead of print)

3 – de Oliveira Andrade PM, de Oliveira Ferreira F, Haase VG. Multidisciplinary perspective for cerebral palsy assessment after an International, Classification of Functioning, Disability and Health training. *Dev Neurorehabil* 2011; 14(4):199-207.

4- Universidade Federal de Minas Gerais. Regulamento do Programa de Pós Graduação em Neurociências. Disponível em <u>www.ufmg.br/neurociencias. Acesso</u> <u>em 31/01/212</u>.

## 4 **RESULTADOS**

Os resultados estão apresentados nos estudos desenvolvidos com o objetivo de operacionalizar os objetivos específicos da presente tese.

# 4.1 ESTUDO 1: PERFIL COGNITIVO, DÉFICITS MOTORES E INFLUÊNCIA DOS FACILITADORES PARA REABILITAÇÃO PARA CRIANÇAS COM DISFUNÇÕES NEUROLÓGICAS

**Referência:** Andrade PMO, Ferreira FO, Vasconcelos AG, Lima EP, Haase VG. Cognitive profile, motor deficits and influence of facilitators for rehabilitation for children with neurological dysfunction. *Rev Paul Pedriatr* 2011; 29(3): 320-27

#### Resumo:

Introdução: A Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) propõe fatores ambientais como integrantes da perspectiva biopsicossocial de atenção à saúde. Durante o planejamento da reabilitação, os profissionais devem identificar os facilitadores para a reabilitação (FR). Objetivos: Investigar se crianças e adolescentes saudáveis e com doenças neurológicas podem ser reunidas em grupos distintos e homogêneos usando como critérios o desempenho cognitivo, o funcionamento motor e as percepções dos pais quanto aos FR. Métodos: Participaram desse estudo 15 crianças saudáveis (C) e 43 pacientes (PC, n = 28; AVC, n = 15), com idade variando entre 5 e 18 anos. Foi utilizado um instrumento com os pais denominado Avaliação dos Fatores Ambientais relacionados à Reabilitação Neurológica Infantil- AFARNI. O comprometimento cognitivo foi avaliado por meio do Mini-Exame do Estado Mental, adaptado para esta faixa etária, e o comprometimento motor foi investigado através de uma avaliação clínica. Para a análise dos dados, foi realizada uma análise de conglomerados e ANOVA. Resultados: A análise de conglomerados identificou quatro grupos com características clínicas e sóciodemográficas distintas, confirmados pela ANOVA (p<0.001). Foi encontrada uma dissociação entre os grupos com relação ao comprometimento cognitivo e motor. Conclusões: Os resultados indicaram que os pais de crianças com maior comprometimento avaliaram de forma mais positiva os FR. A qualificação dos FR por meio da AFARNI e avaliação cognitiva com auxílio do MEEM pode contribuir para identificar as necessidades de suporte para crianças com deficiências neurológicas que apresentam comprometimento cognitivo e motor, operacionalizando a perspectiva biopsicossocial da OMS.

Palavras-chave: disfunções neurológicas; Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF); Mini-Exame do Estado Mental (MEEM), comprometimento motor, análise de conglomerados

#### Abstract

Introduction: For the rehabilitation planning, professionals must identify the rehabilitation facilitators (RF). The International Classification of Functioning, Disability and Health (ICF) offer environmental factors as integrators of the biopsycossocial perspective of health care. Objectives: To investigate whether healthy children and adolescents suffering from neurological diseases (cerebral palsy (CP) and stroke) can be grouped into distinct and homogeneous groups using criteria such as cognitive performance, motor functioning and parents perceptions about the RF. Methods: Sample was comprised by 15 healthy children (Controls - C) and 43 patients (CP, n = 28; stroke, n = 15), aged from 5 to 18 years old. The AFARNI – Environment Factors Assessment related to the Children Neurologic Rehabilitation - was used to assess parents' perception of the RF. Cognitive impairment was assessed using the MMSE - Mini Mental Status Examination - adapted for children and the motor impairment was assessed by a clinical evaluation. Cluster analysis and one way ANOVA were conducted. Results: Cluster analysis identified four groups with clinical and sociodemographic distinct patterns, confirmed by ANOVA (p < 0.001). We found dissociation between cognitive and motor functions. Conclusions: The results indicated that parents of children with severe motor and cognitive impairment evaluated more positively RF, considering the relevance of these factors to promote the development of individuals with neurological disorders. The qualification of RF can help to identify the needs of children with neurological disabilities and cognitive impairment applying the WHO biopsychosocial perspective.

Keywords: neurological diseases; ICF; MMSE; motor impairment; rehabilitation, cluster analysis

### INTRODUÇÃO

A chave do sucesso terapêutico e preventivo em reabilitação de condições crônicas é compreender a relação entre as deficiências nas estruturas e funções do corpo e os fatores psicossociais, para a seleção dos problemas alvo que serão abordados pela equipe de saúde<sup>1</sup>. Para isso, durante o planejamento da intervenção pela equipe de reabilitação, os profissionais devem registrar os componentes da saúde com potencial de melhora e os recursos ambientais necessários para a reabilitação. A ausência de fatores ambientais facilitadores, além de representar uma barreira para a funcionalidade da criança ou adolescente, pode ser interpretada como uma negligência do poder público, da família ou dos profissionais da saúde. Por outro lado, ações assistencialistas, paternalistas ou protetoras podem limitar o desenvolvimento da autonomia da criança, fazendo com que essas ações sejam consideradas como barreiras. Diante disso, a extensão na qual um determinado fator será considerado como barreira ou facilitador dependerá da real necessidade para cada caso<sup>2</sup>. Por isso, a avaliação dos fatores ambientais necessariamente envolve a perspectiva do contexto vivido pela criança ou adolescente.

A Classificação Internacional de Funcionalidade, Incapacidade e Saúde (CIF) da Organização Mundial de Saúde<sup>3</sup> considera que os fatores ambientais podem atuar como facilitadores ou barreiras na adaptação do indivíduo em diferentes condições de saúde. Os Facilitadores para a Reabilitação (FR) foram definidos como fatores ambientais relevantes para a promoção da funcionalidade e prevenção de incapacidades. Considere-se, como exemplo, um caso de acidente vascular cerebral (AVC) ocorrido na infância, em que após o comprometimento da independência para a comunicação, mobilidade e cuidado pessoal o paciente pode se inserir em uma situação ambiental facilitadora para a recuperação das habilidades perdidas ou em um contexto que pode inibir a expressão de processos neuroplásticos<sup>2</sup>. Diante disso, cabe à equipe de reabilitação identificar as capacidades e limitações do indivíduo em âmbito pessoal e ambiental, procurando intervir na medida do possível em seu ambiente.

A literatura que examina a avaliação da funcionalidade em casos de AVC infantil e PC apresenta como foco principal a avaliação da etiologia das doenças<sup>4,5,6,7</sup> ou nas deficiências e limitações relacionadas com os quadros neurológicos<sup>8,9,10,11,12,13</sup>. Por isso, são necessários estudos para a elaboração de instrumentos de avaliação capazes de registrar as necessidades das crianças para uma intervenção ambiental (medicamentos, fisioterapia, terapia ocupacional, integrada psicologia, fonoaudiologia, abordagem familiar. programas educativos específicos, equipamentos de auxílio para a mobilidade, etc) para atuarem como facilitadores no desempenho funcional dessas crianças. A literatura apresenta-se escassa ao considerar o uso da CIF para a avaliação dos fatores ambientais como facilitadores para a reabilitação em casos de disfunções neurológicas. Diante disso, o presente estudo pretende identificar critérios clínicos (desempenho cognitivo e percepções dos pais quanto os FR) que possam ajudar na classificação de pacientes em grupos distintos e homogêneos. A identificação de tais grupos tem relevância para a reabilitação, uma vez que os diferentes grupos podem ter demandas distintas de atendimento.

O objetivo do presente estudo foi investigar se crianças e adolescentes saudáveis e com doenças neurológicas (paralisia cerebral, PC e sequela de acidente vascular cerebral, AVC) podem ser reunidas em grupos distintos e homogêneos usando como critérios o desempenho cognitivo, o funcionamento motor e as percepções dos pais quanto aos facilitadores para a reabilitação.

### MÉTODOS

O estudo obteve a aprovação do Comitê de Ética em Pesquisa (COEP) da UFMG, protocolo 139/07 e do COEP da Rede FHEMIG pelo parecer 397/2006.

#### a) Participantes

Foram determinados critérios de inclusão para cada grupo. Os critérios de inclusão para participação no estudo para todos os grupos foram: idade entre cinco e dezoito anos e aceitar e assinar o Termo de Consentimento Livre e Esclarecido. Os critérios de inclusão para o grupo controle foram não apresentar problemas neurológicos e freqüentar o sistema regular de ensino. Os critérios de inclusão para o grupo clínico foram ter o diagnóstico de AVC e PC estabelecido por um médico neurologista. Os diagnósticos foram confirmados através do estudo dos prontuários médicos de todos os pacientes nas instituições em que foram identificados.

O cálculo do tamanho amostral foi realizado a partir dos resultados de 10 crianças avaliadas em um estudo piloto (5 controles e 5 clínicos). Foi estimado o tamanho amostral necessário para alcançar poder estatístico de 90%. Como a magnitude de efeito<sup>14</sup> encontrada na comparação entre os grupos foi elevada (valores d superiores a 1,4), verificou-se que a amostra necessária para atingir um poder estatístico de 90% seria de 10 participantes por grupo<sup>14</sup>. Dessa forma, a amostra empregada no estudo foi superior ao mínimo necessário para atingir poder estatístico.

Participaram desse estudo 58 crianças cujas idades variaram entre 5 a 18 anos. A amostra foi composta por 15 estudantes de escolas públicas de Belo Horizonte (grupo controle) e 43 crianças com diagnóstico de doença neurológica (grupo clínico), incluindo 28 pacientes com PC e 15 crianças com seqüelas de AVC. Os casos de PC foram identificados na Associação dos Pais e Amigos dos Excepcionais (APAE). Já os casos de AVC foram identificados no serviço de Hematologia do Hospital Borges da Costa e no banco de dados do Centro Geral de Pediatria (CGP-FHEMIG). Foi realizada a busca de casos de AVC infantil identificados nos hospitais, por meio da consulta de todos os prontuários entre os anos de 2001 e 2007. As informações a respeito das características sócio-demográficas dos participantes de cada quadro clínico estão resumidas na Tabela 1.

Grupos	Ν	Sexo (% feminino)	ldade (anos) média (dp)	Nível sócio-econômico média (dp)
Controle	15 60%		7.9	14.1
			(1.2)	(4.7)
Clínico – PC	2 28	50%	11.1	10.4
	20		(4.0)	(3.7)
	45	409/	9.5	14.6
	10	40 /0	3.1)	(5.8)

Tabela 1 - Características sócio-demográficas dos participantes separadas por quadro clínico

#### b) Instrumentos:

#### Questionário de avaliação da condição sócio-econômica

Realizou-se o levantamento da condição sócio-econômica das famílias participantes. Utilizou-se o Critério de Classificação Econômica Brasil (CCEB), proposto pela Associação Brasileira de Empresas de Pesquisa<sup>15</sup>.

#### Mini-Exame do estado Mental (MEEM)

JAIN E PASSI<sup>16</sup> adaptaram e validaram o MEEM para crianças com idade entre três e 14 anos, a partir de um sistema de escores para avaliar deficiências cognitivas. O instrumento avalia as funções mentais da linguagem, orientação espacial e temporal, atenção, memória e praxia construtiva<sup>17</sup>. Jain e Passi<sup>16</sup> estabeleceram como ponto de corte para déficit cognitivo um escore inferior a dois desvios padrão abaixo da média.

# <u>Avaliação dos fatores ambientais relacionados à reabilitação neurológica infantil -</u> <u>AFARNI</u>

A AFARNI, composta por 26 itens, foi desenvolvida por ANDRADE & HAASE<sup>18</sup> baseada no modelo da CIF em que os pais avaliaram fatores ambientais como facilitadores ou barreiras para o desenvolvimento e/ou reabilitação de seus filhos. Os pais deveriam realizar a qualificação dos fatores ambientais através de uma escala ordinal como barreiras ou facilitadores. Dessa forma, o fator ambiental poderia ser considerado facilitador (leve, moderado, considerável, completo) ou barreira (leve,

moderada, grave, completa). Havia ainda a possibilidade de avaliar o fator ambiental como neutro, ou seja, não era percebido como facilitador ou como barreira à adaptação da criança ou adolescente para atividades da vida diária<sup>3</sup>. Os escores altos indicam a percepção dos FR como facilitadores. Para facilitar a compreensão das categorias pelos pais e crianças, algumas categorias de terceiro nível da CIF foram incluídas na AFARNI (medicamento, alimentação, serviços de saúde, serviços de educação, serviço prestado pelo setor público) e algumas categorias de terceiro nível foram elaboradas pelos pesquisadores no item de profissionais da saúde (e355), com o objetivo de definir de forma mais precisa o profissional (terapeuta ocupacional, psicólogo, fisioterapeuta, médico, fonoaudiológo, enfermeiro). No item de família imediata (e310), as subcategorias pai, mãe, responsável e irmãos foram discriminadas<sup>18</sup>.

#### c) Procedimentos de coleta de dados

A coleta de dados a respeito da percepção dos pais sobre os FR foi realizada por meio de entrevista individual estruturada com os pais ou responsáveis pela criança, empregando a AFARNI<sup>18</sup>. A avaliação do comprometimento motor foi realizada por meio da classificação topográfica. A avaliação cognitiva foi realizada empregando o MEEM na avaliação das crianças.

### d) Procedimentos de análise dos dados:

A análise dos dados foi realizada no programa estatístico *Statistical Package for the Social Sciences* (SPSS), versão 15.0. Inicialmente, foram realizadas estatísticas descritivas para caracterização do perfil sócio-demográfico dos participantes da amostra e análise de variância univariada para verificar se existiam diferenças entre os grupos delimitados a partir do diagnóstico de disfunção neurológica. Foi realizado também uma análise preliminar da acurácia do MEEM para a amostra de crianças por meio da análise da área sob a curva ROC.

Posteriormente, para tornar as comparações mais parcimoniosas, optou-se por agrupar os itens dos fatores ambientais da AFARNI em duas variáveis compostas pelas médias do instrumento, denominadas Fatores Ambientais Básicos (FAB) e Fatores Ambientais Específicos (FAE). A variável FAB foi composta pelo cálculo da média dos itens que são essenciais para o desenvolvimento e funcionalidade de todos os participantes, independente da condição clínica, tais como alimentação, pais, irmãos, família ampliada, amigos, produtos e tecnologias para brincar, serviços educacionais, professores, serviços de transporte e atitudes sociais. Já a variável FAE foi composta pelo cálculo da média dos itens relacionados com cuidados específicos da saúde, tais como profissionais de saúde, educação especial, uso de órteses e próteses, etc.

No intuito de agrupar os participantes em grupos homogêneos, foram realizadas análises exploratórias por meio da técnica de análise de conglomerados (método Ward)<sup>19,20</sup>, utilizando como variáveis critério os escores padronizados do grau de comprometimento motor, percepção dos fatores ambientais e MEEM. Foram utilizados os escores padronizados (escore z) com o intuito de evitar vieses na análise de conglomerados, uma vez que as variáveis são expressas em escalas distintas. Para a confirmação dos resultados obtidos por meio da análise de conglomerados foi utilizado o método de Análise de Variância (ANOVA univariada) com correções de Bonferroni para as comparações múltiplas, a fim de avaliar as diferenças encontradas.

### RESULTADOS

### Análise da Acurácia do MEEM adaptado para crianças

A adaptação do MEEM para crianças mostrou-se adequada para avaliar o funcionamento cognitivo geral, uma vez que as análises da área sob a curva ROC demonstraram que o instrumento apresentou uma acurácia de 94% para discriminar os déficits cognitivos de crianças com lesão cerebral (PC e AVC) e controles (área sob a curva=0,94; IC95%inf=0,87; IC95%sup=0,99; p<0.001). Dessa forma, o MEEM mostrou-se acurado e sensível para detectar déficits cognitivos em crianças, de forma rápida e simples, mostrando-se um instrumento apropriado para ser utilizado como instrumento de rotina em pediatria.

### Análise descritiva

A análise descritiva e a comparação entre pacientes e controles (ANOVA univariada) são apresentadas na **Tabela 2**. Subdividiram-se os indivíduos de acordo com o diagnóstico clínico.

Variáveis		Diagnostico Clínico			Comparação	
		Controles	PC	AVC	entre os grupos	
MEEM	média	33.5	8.3	24.1	F=39.45;	
	(dp)	(3.9)	(10.9)	(9.7)	p<0.001; gl=2	
Fatores ambientais	média	21	22.5	21.3	F= 0.13;	
básicos	(dp)	(7.2)	(9.8)	(13.15)	p=0.88. gl =2	
Fatores ambientais	média	6.6	23.3	10.9	F=30.27;	
específicos	(dp)	(6.9)	(7.4)	(7.3)	p<0.001; gl=2	
Comprometimento motor	%	N= 100% H= 0 Q=0	N=0 H=25,9% Q=74,1%	N= 20% H = 80% Q= 0	χ <sup>2</sup> =71.57; p<0.001; gl=6	

Tabela 2: Análise descritiva e comparativa (ANOVA) das respostas da AFARNI e desempenho no MEEM dos três grupos participantes (controles, PC, AVC)

\* N - Nenhum; H = Hemiplegia; Q - Quadriplegia
A comparação objetivou verificar se existem diferenças significativas entre os três grupos com relação às variáveis estudadas. Foram encontradas diferenças significativas entre os grupos nos escores médios do MEEM, no grau de comprometimento motor e na percepção dos FAE (p<0,001), como pode ser observado na Tabela 2. Entretanto, nos FAB não foram encontradas diferenças significativas entre os grupos, o que pode ser explicado pelo fato de que esses fatores são igualmente relevantes para os três grupos.

Realizando a análise da magnitude de efeito<sup>14</sup> dos resultados finais para o MEEM e FAE, foram obtidas magnitudes de efeito elevadas (valores de d<sup>14</sup> entre 1,59 e 2,42), o que revela que as diferenças cognitivas e da percepção dos facilitadores entre os grupos é elevada e clinicamente significativa, indicando ainda que o estudo apresenta poder estatístico superior a 96%<sup>14</sup>.

Os coeficientes de correlação de Spearman obtidos entre os escores no MEEM, na avaliação do comprometimento motor e na percepção dos FAE foram moderados (em torno de 0,70). As correlações obtidas entre as variáveis e os FAB não foram significativas (p>0,05). Além disso, observou-se que não foram encontradas diferenças significativas entre os grupos nos FAB (F= 0,13; p=0,88; gI =2), uma vez que tais fatores são relevantes para a funcionalidade dos três grupos considerados nesse estudo. Diante disso, por não informarem sobre características distintas no perfil dos três grupos, optou-se por não incluir os FAB na formação dos conglomerados.

#### Perfil dos conglomerados formados:

A análise de conglomerados resultou em uma solução ideal com quatro grupos, que

são demonstrados na Tabela 3.

Tabela 3: Perfil dos conglomerados formados com relação ao escore no MEEM, s facilitadores ambientais específicos, e comprometimento motor.

	Conglomerado 1 n=18		Conglomerado 2 n=17		Conglomerado 3 n=7		Conglomerado 4 n= 15	
	média	dp	média	dp	média	dp	média	dp
MEEM	31.89	6.04	23.76	7.41	11.86	10.29	0	0
Fatores ambientais específicos	6.28	6.71	14.35	8.14	23.14	2.73	25.53	7.15
Comprometimento Motor	N =94.4% H = 5.6% Q = 0%		N = 0% H = 70.6% Q = 29.4%		N = 14.3% H = 85,7% Q = 0%		N = 0% H = 0% Q = 100%	

\* N - Nenhum; H = Hemiplegia; Q - Quadriplegia

A partir dos dados apresentados na Tabela 3, percebeu-se que os conglomerados diferiram de forma nítida nos escores médios obtidos no MEEM, na avaliação do comprometimento motor e nos FAE. Na Tabela 4, a seguir, apresenta-se o perfil sócio-demográfico e aspectos clínicos dos quatro conglomerados obtidos.

No primeiro conglomerado, agruparam-se os participantes com melhor desempenho no MEEM, baixo grau de comprometimento motor e menores resultados na avaliação dos FAE. Todas as crianças saudáveis da amostra foram alocadas nesse grupo. Apenas três crianças com problemas neurológicos – AVC – foram incluídas no grupo 1. O Conglomerado 1 também se caracterizou pela média de idade mais jovem e distribuição homogênea entre meninos e meninas.

Conglomerados	Ν	Sexo (% feminino)	Idade	Diagnóstico	Comprometimento motor*
Grupo 1	18	55.6%	m=7.83 (dp=1.54)	C = 83.3% PC = 0% AVC = 16.7%	N =94.4% HE = 5.6% HD = 0% Q =0%
Grupo 2	17	64.7%	m=11.24 (dp=3.90)	C = 0% PC = 41.2% AVC = 58.8%	N =0% HE = 17.6% HD = 52.9% Q = 29.4%
Grupo 3	7	57.10%	m=11.57 (dp=3.91)	C = 0% PC = 71.4% AVC = 28.6%	N =14.3% HE = 42.9% HD= 42.9% Q = 0%
Grupo 4	15	26.70%	m=9.67 (dp=3.44)	C = 0% PC = 100% AVC = 0%	N = 0% HE =0% HD = 0% Q = 100%

Tabela 4: Características clínicas e sócio-demográficas dos conglomerados formados

\* N - Nenhum; HE - Hemiplegia esquerda; HD - Hemiplegia direita; Q – Quadriplegia – C = Controle

Os Conglomerados 2 e 3 foram compostos apenas por pacientes, incluindo crianças com PC e AVC em diferentes proporções. Os grupos se assemelham em relação à média de idade dos participantes e predominância do sexo feminino, mas diferenças importantes foram observadas. O segundo conglomerado foi formado por participantes com escores médios no MEEM e na avaliação dos FAE, indicando melhores resultados do que os encontrados no grupo 3. Entretanto, o grupo 2 apresentou maior comprometimento motor em comparação com o grupo 3, indicando que o desempenho motor e cognitivo são dimensões dissociadas na amostra estudada.

No quarto conglomerado, foram agrupadas apenas as crianças com diagnóstico de PC. O grupo apresentou uma faixa etária média e a menor proporção de

participantes do sexo feminino. O grupo 4 agrupou crianças com maior comprometimento cognitivo e motor, com os piores desempenhos no MEEM, maior comprometimento motor e os escores mais altos na avaliação dos FAE.

## Análise de variância (ANOVA Univariada)

Os resultados obtidos por meio da análise de conglomerados foram investigados por meio da ANOVA Univariada. Houve diferenças significativas entre os grupos considerando os escores no MEEM (F[3] = 75,68, p<0,001), o grau de comprometimento motor (F[3] = 96,92, p<0,001) e a percepção dos FAE (F[3] = 23,68, p<0,001).

Com o intuito de detalhar esse achado e identificar a natureza das diferenças, foram realizadas comparações múltiplas entre os diversos grupos e ajuste pelo método de Bonferroni. Os resultados indicaram a presença de diferenças estatisticamente significativas entre os quatro grupos nas três variáveis consideradas (MEEM, comprometimento motor e FAE; p<0,001), o que confirma a adequação dos resultados da análise de conglomerados. No entanto, observou-se a ausência de diferença entre os grupos 3 e 4 com relação a avaliação dos FAE, apesar dos grupos diferirem estatisticamente nos aspectos cognitivos e motores. Esse resultado pode indicar que, a partir de determinado nível de comprometimento cognitivo e motor, os FAE passam a ser considerados facilitadores igualmente importantes, tanto para as pessoas com comprometimento moderado, quanto para os participantes com comprometimento grave.

# DISCUSSÃO

Diante de um quadro clínico heterogêneo com um conjunto de deficiências e limitações, os fatores ambientais precisam atuar como facilitadores para a melhora da funcionalidade das crianças com alguma disfunção neurológica<sup>18</sup>. A melhor maneira de minimizar o desafio de classificar a funcionalidade de uma criança com disfunções neurológicas é abarcar um sistema multi-axial de classificações que incorporem diferentes domínios<sup>21</sup>. A CIF pode ser uma referência para a avaliação do impacto funcional e psicossocial de diferentes situações clínicas, logo, instrumentos baseados nessa classificação precisam ser desenvolvidos com o intuito de permitir a utilização desta classificação na prática clínica <sup>1,2,18</sup>. O presente estudo contribui para essa lacuna ao trazer evidências de acurácia de instrumentos adaptados para crianças brasileiras que possam ser utilizados por profissionais de saúde de modo interdisciplinar, a saber, o MEEM adaptado para crianças e a AFARNI. Observou-se que a adaptação do MEEM mostrou-se adequada para rastrear de forma simples e rápida o funcionamento cognitivo de crianças, sendo sensível para discriminar entre o funcionamento cognitivo de crianças com lesões cerebrais e controles. Considerando a relevância de se obter um rastreio cognitivo breve de crianças, é possível que esse instrumento seja utilizado como procedimento de rotina em atendimentos pediátricos. Já a AFARNI mostrou-se um instrumento sensível para identificar facilitadores e barreiras relacionados à reabilitação neurológica infantil.

É interessante notar a dissociação entre o funcionamento cognitivo e motor, que pode ser observado mais detalhadamente na comparação entre os Conglomerados

2 e 3, indicando que o comprometimento motor não está associado ao comprometimento cognitivo. Considerando que a classificação da PC e do AVC está vinculada ao grau de comprometimento motor, é importante enfatizar a necessidade de complementar a avaliação motora com a avaliação cognitiva. A avaliação abrangente evita vieses de diagnósticos estritamente vinculados aos aspectos motores e que muitas vezes negligenciam a capacidade cognitiva dos pacientes.

A avaliação cognitiva e motora do presente estudo revelou que as crianças com PC apresentaram pior desempenho comparativamente às crianças que sofreram AVC. Dentre os fatores ambientais que podem contribuir para o processo de reabilitação, um aspecto relevante é o nível sócio-econômico. A análise dos resultados aponta que as crianças com PC do presente estudo apresentaram nível sócio-econômico inferior ao grupo controle e às crianças que sofreram AVC. Dessa forma, é importante considerar que o status sócio-econômico familiar pode ser uma barreira ou um facilitador para o processo de reabilitação, merecendo ser considerado no atendimento neuropediátrico.

Ressalta-se que a avaliação dos FAE como facilitadores foi mais elevada para os participantes do Conglomerado 3, que apresentaram maior comprometimento cognitivo e menor comprometimento motor em comparação com o Conglomerado 2. Analisando a distribuição dos participantes nos conglomerados, observa-se que à medida que o comprometimento cognitivo da criança aumenta, a avaliação dos FAE como facilitadores pelos pais eleva-se. Pode-se inferir por esse resultado que os pais de crianças com déficits cognitivos percebem de forma mais significativa a necessidade de apoio de profissionais e serviços especializados. A qualificação dos

FAE pode contribuir para identificar as necessidades de suporte em crianças com deficiências neurológicas e comprometimento cognitivo.

O foco da avaliação deve apresentar as distintas prioridades, conforme o contexto ambiental ou pessoal que a criança está vivenciando. Por isso, a padronização da avaliação da funcionalidade da criança deve ser ampla o suficiente para considerar os diferentes fatores contextuais a que a criança está exposta, pois as exigências para a realização de atividades e participação ocorrerão de acordo com as etapas de desenvolvimento da criança.

A maioria dos estudos sobre a participação da criança ou adolescente com PC estão relacionados com questões lineares vinculadas ao tratamento <sup>22-25</sup> ou à educação<sup>26, 27</sup>. O único estudo que procurou envolver as questões da família, escola e reabilitação empregando a CIF para casos de PC foi o estudo de caso longitudinal descrito por Palisano<sup>28</sup>. Entretanto, o estudo de Palisano<sup>28</sup> não apresentou uma proposta para a avaliação das barreiras e facilitadores envolvidos em casa, na escola e na comunidade. Diante de um quadro clínico heterogêneo com um conjunto de deficiências e limitações, os fatores ambientais precisam atuar como facilitadores para a melhora da funcionalidade das crianças com diagnóstico de disfunções neurológicas. Assim, a família, os profissionais de saúde, os amigos, os professores e a comunidade em geral podem contribuir para a inserção social da criança. Por outro lado, são necessários estudos para identificar as barreiras que estas crianças atividades de reabilitação orientadas pelos profissionais da saúde e de recreação e lazer com a família e amigos.

As barreiras específicas para crianças com PC não têm sido sistematicamente avaliadas, pois os estudos se concentram na avaliação das estruturas e funções do corpo, sendo pouco conhecidos os efeitos das intervenções nos níveis de atividade e participação das crianças com PC<sup>29</sup>. Por exemplo, o condicionamento cárdio-respiratório e o fortalecimento muscular são frequentemente indicados para casos de PC. Entretanto, a maioria das crianças com deficiências não tem acesso a serviços para a prática de atividades físicas, o que constitui uma barreira para a melhora da função cárdio-respiratória<sup>29</sup>.

Um sistema multi-axial de classificação deve ser formulado e precisa ser validado no futuro através de um consenso sobre o atendimento neuropediátrico<sup>21</sup>. O uso do MEEM e da AFARNI no atendimento pediátrico poderá contribuir para o avanço na avaliação da funcionalidade de crianças com diagnóstico de disfunções neurológicas para além dos aspectos motores e atender a perspectiva biopsicossocial. A aplicação do modelo multidimensional de funcionalidade e incapacidade da CIF durante a prática clínica poderá auxiliar o processo de avaliação e intervenção em neuropediatria.

# Referências

1- Stucki, G. International classification of functioning, disability, and health (ICF): a promising framework and classification for rehabilitation medicine. Am J Phys Med Rehabil. 2005; 84:733-40.

2- Andrade PMO, Ferreira, FO, Haase, VG. O uso da CIF através do trabalho interdisciplinar no AVC pediátrico: relato de caso. Contextos Clínicos. 2009;2: 27-39.

3- World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.

4- Chabrier S, Husson B, Lasjaunias P, Landrieu P, Tardieu M. Stroke in childhood: outcome and recurrence risk by mechanism in 59 patients. J Child Neurol. 2000; 15: 290-4.

5- Kirkham, FJ, Hogan, AM. Risk factors for arterial ischemic stroke in childhood. CNS Spectr. 2004; 9: 451-64.

6- Lanthier S, Carmant L, David M, Larbrisseau A, de Veber G. Stroke in children: the coexistence of multiple risk factors predicts poor outcome. Neurology. 2000; 54:371-8.

7- Bax M, Goldstein M, Rosenbaum P, Leviton A, Paneth N, Dan B, et al. Proposed definition and classification of cerebral palsy, April 2005. Dev Med Child Neurol. 2005; 47: 571-6.

8- Russell DJ, Rosenbaum PL, Avery LM, Lane M. Gross Motor Function Measure (GMFM-66 & GMFM-88) User's Manual. London, UK: Mac Keith Press; 2002

9- Taylor, F. National Institute of Neurological Disorders and Stroke (U.S.), Office of Science and Health Reports. *Cerebral palsy*: hope through research. Bethesda, Md.: The Institute, 2001.

10 - Gordon AL, Ganesan V, Towell A, Kirkham FJ. Functional outcome following stroke in children. J Child Neurol. 2002; 17:429-34.

11- Barreirinho S, Ferro A, Santos M, Costa E, Pinto-Basto J, Sousa A, et al. Inherited and acquired risk factors and their combined effects in pediatric stroke. Pediatric Neurology. 2003; 28:134-8.

12- Hutchison JS, Ichord R, Guerguerian AM, Deveber G. Cerebrovascular disorders. Semin Pediatr Neurol. 2004; 11:139-46.

13- Krigger, KW. Cerebral palsy: an overview. Am Fam Physician. 2006; 73:91-100

14 - Cohen, J. Quantitative Methods in Psychology: a power prime. Psychological Bulletin. 1992; 112: 155-59.

15- Associação Brasileira de Empresas de Pesquisa - ABEP. Critério de Classificação Econômica Brasil. [2003]. Disponível em: <a href="http://www.abep.org/codigosguias/ABEP\_CCEB.pdf">http://www.abep.org/codigosguias/ABEP\_CCEB.pdf</a>>. Acesso em: 10 jul. 2006.

16- Jain, M, Passi, GR. Assessment of a modified mini-mental scale for cognitive functions in children. Indian Pediatr. 2005; 42: 907-12.

17- Folstein, MF; Folstein, SE, MC, Hugh, PR. Minimental state: a practical method for grading the cognitive state of patients for the clinician. J Psychiatr Res. 1975; 12:189-98.

18 - Andrade, PMO; Haase, VG. Avaliação da funcionalidade em crianças e adolescentes com Paralisia Cerebral e Acidente Vascular Cerebral: um estudo exploratório. Dissertação de Mestrado apresentada no Programa de Pós Graduação em Ciências da Saúde: Área de Concentração em Saúde da Criança e do Adolescente da Universidade Federal de Minas Gerais; 2008.

19- Everitt, B. Cluster Analysis. 3th ed. New York: Halsted Press; 1993.

20- Mingoti, SA. Análise de dados através de métodos de estatística multivariada: uma abordagem aplicada. Belo Horizonte: Editora UFMG; 2005.

21- Shevell MI, Majnemer A, Poulin C, Law M. Stability of motor impairment in children with cerebral palsy. Dev Med Child Neurol. 2008; 50: 211-15.

22- Odman, PE, Oberg, BE. Effectiveness and expectations of intensive training: a comparison between child and youth rehabilitation and conductive education. Disabil Rehabil. 2006; 28: 561-70.

23- Saleh MN, Korner-Bitensky N, Snider L, Malouin F, Mazer B, Kennedy E *et al.* Actual vs. best practices for young children with cerebral palsy: a survey of paediatric occupational therapists and physical therapists in Quebec, Canada. Dev Neurorehabil. 2008; 11:60-80.

24- Siebes RC, Ketelaar M, Gorter JW, Wijnroks L, De Blécourt AC, Reinders-Messelink HA *et al.* Transparency and tuning of rehabilitation care for children with cerebral palsy: a multiple case study in five children with complex needs. Dev Neurorehabil. 2007; 10: 193-204.

25-Wright FV, Rosenbaum PL, Goldsmith CH, Law M, Fehlings DL. How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? Dev Med Child Neurol. 2008; 50: 283-9.

26- Beckung, E, Hagberg, G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. Dev Med Child Neurol. 2002; 44: 309-16.

27- Schenker, R, Coster, W, Parush, S. Personal assistance, adaptations and participation in students with cerebral palsy mainstreamed in elementary schools. Disabil Rehabil. 2006; 28: 1061-69.

28- Palisano, RJ. A collaborative model of service delivery with movement disorders: a framework for evidence-based decision making. Phys Ther. 2006; 86: 1295-305.

29- Fowler EG, Kolobe TH, Damiano DL, Thorpe DE, Morgan DW, Brunstrom JE *et al.* Promotion of physical fitness and prevention of secondary conditions for children with cerebral palsy: section on pediatrics research summit proceedings.

# 4.2 ESTUDO 2: CONTENT IDENTIFICATION OF THE INTERDISCIPLINARY ASSESSMENT OF CEREBRAL PALSY USING THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH AS REFERENCE

**Referência:** Andrade PM, Oliveira Ferreira F, Mendonça AP, Haase VG. Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. *Disabil Rehabil*, 2012; (Epub ahead of print)

# Abstract

Purpose: to identify relevant items and most frequents categories related to functioning and disability recorded by professionals involved in rehabilitation of children with cerebral palsy (CP) and to assess the filling of the records. Methods: A retrospective cross-sectional study based on the written documents provided by an interdisciplinary rehabilitation team. Participated in the study 40 patients with CP. aged 10 months to 17 years. Two raters extracted information from the patients' medical documents as recorded by physicians, physiotherapists, occupational therapists, speech therapists, social workers, psychologists and dieticians using the ICF-CY. Patients' records were scored (+functioning, -disability and \*environmental factors) using 27 ICF-CY items to assess the filling of the records. Results: Eightyone items in the medical records [body structure(15), bodily functions(32), activity(24) and environmental factors(10)] were identified as related to the evaluation of the different professions involved with neuro-rehabilitation. Physiotherapy and occupational therapy provided the most comprehensive assessments performed. Fourteen categories had a minimum frequency of 40% during the registration process. Conclusions: The content of the information involves categories related to the structures and body functions, activities and environmental factors. The information follows a heterogeneous pattern in content and number of categories. The most frequent items can comprise a set of codes for triage of CP. It is necessary to establish an interdisciplinary consensus based on ICF-CY for systematize the information's record.

**Key-words:** International Classification of Functioning, Disability and Health, ICF, ICF-CY, cerebral palsy, rehabilitation

Short Title: Interdisciplinary assessment of CP using the ICF

# Implications for Rehabilitation:

- The 81 ICF-CY categories identified can comprise a set of codes for cerebral palsy's assessment in the rehabilitation practice

- Professionals must identify and record not only the negative aspects, but also the positive aspects related to the functioning of children with CP

- A standardized assessment based on the ICF model may contribute to a more efficient functioning evaluation, in agreement with the biopsychosocial model

- There is a need for more specific training and education on the use of the ICF

**Referência:** Andrade PM, Oliveira Ferreira F, Mendonça AP, Haase VG. Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. *Disabil Rehabil*, 2012; (Epub ahead of print)

# Introduction

There are different interdisciplinary efforts related to the care of children with cerebral palsy (CP) [1-4]. The biopsychosocial approach recommended by the World Health Organization (WHO) has been used to guide clinical reasoning and the organisation of interdisciplinary care in neurorehabilitation services [5, 6]. The International Classification of Functioning, Disability and Health (ICF) proposes a comprehensive view of health, including biological, individual and social perspectives, rather than limiting assessment to biological characteristics alone [7, 8]. ICF provides a common terminology for health professionals, comprising components with a neutral language. Therefore, rehabilitation professionals can rate the positive aspects (functioning) and negative aspects (disability) related to health [7].

The use of ICF facilitates interdisciplinary communication [9, 10] and contributes to the definition of the responsibilities of health professionals [11, 12]. In addition, ICF can be used to define the therapeutic planning of the health team [13, 14] and the choice of assessment tools. The chapters related to ICF activity and participation were used for the definition of the responsibilities of professionals involved in the process of neuro-rehabilitation [15]. This practice allows interdisciplinary teamwork and can avoid redundant and unnecessary assessments.

One difficulty concerning clinical practice is the inconsistency between the goals set by health professionals and the needs and complaints requested by patients. There is a need for greater transparency and understanding between the process of paediatric treatment and the problems perceived by parents and children. The lack of transparency of the goals of treatment between professionals and parents, as well as the lack of information in the records of the children, were identified as barriers to the rehabilitation process [16, 17].

ICF has been suggested as a model and framework for description in medical records and for the development of databases to assist with health services' management [18, 19]. Usually, professionals' interventions focus on impairment and function, offering little attention to activities related to recreation and leisure [20] and failing to incorporate the biopsychosocial approach as proposed by the WHO [7].

To the best of our knowledge, no study has investigated the use of ICF in a Brazilian health care service. The low use of the ICF is related to its nature as a recent and complex classification that presents difficulties in clinical operationalisation [21]. The functionality evaluations in the Brazilian rehabilitation services are not systematised according to the WHO biopsychosocial perspective [22, 23].

To date, there is no ICF core set for CP. One study identified items and compared the content of quality of life measures for CP [24]. The development of core sets requires the completion of preliminary studies for formal decision-making and consensus [25]. The identification of the contents of the functional evaluation of an interdisciplinary team of neuro-rehabilitation services can help as a preliminary study to define core sets for CP. Furthermore, knowledge of written medical records may contribute to the development of an electronic medical record that can help to facilitate the implementation of the ICF model as the operational reality of a rehabilitation service. Thus, the relevant items will be identified and could be feasible for evaluation and description in records during the actual clinical practice. The

objectives of this study were: a) to identify relevant items and most frequent categories related to functioning and disability recorded by professionals involved in rehabilitation of children with CP and b) to assess the filling of the records for each area involved in the neuro-rehabilitation of CP.

## Methods

The present work is a retrospective cross-sectional study based on the written documents provided by an interdisciplinary rehabilitation team. The research was conducted at Diamantina, Minas Gerais, Brazil. The study was developed in a public rehabilitation centre, a tertiary-care paediatric neuro-rehabilitation unit which serves children from the Jequitinhonha Valley, a region with a low Human Developmental Index (HDI). The HDI is a composite statistic index used by the United Nations to rank cities, regions and countries by level of "human development". To calculate the HDI results of education, life expectancy and per capita income are considered [26].

Twenty-five professionals from different areas work at the rehabilitation centre, including physicians (PHY), physiotherapists (PT), occupational therapists (OT), speech therapists (ST), social workers (SW), psychologists (PSY) and dieticians (DT). The identification of items related to functioning and disability from medical records and the assessment of filling of the records followed five steps as shown in Figure 1.



Fig 1 - Flow of the methods employed

#### a) Identification of cases

Records of 40 cases of CP (50% female) were analysed (14 hemiplegic, 11 diplegic, 15 quadriplegic), all of which were admitted by the Rehabilitation Center from the year 2005 to 2009. Age ranged from 10 months to 17 years old.

# b) Information extraction of medical record (data collection)

The content of the admission assessment was analysed, extracting information about every areas that were investigated by the professionals in the first evaluation of the child. We extracted information from the patients' medical records as provided by physicians, physiotherapists, occupational therapists, speech therapists, social workers, psychologists and dieticians. Medical records information was collected in full in standardized forms.

#### c) Linking of items with ICF-CY

In the present study the ICF-CY was used, as this classification is more suitable for children and young people than the ICF. The ICF-CY has been developed to be structurally consistent with the ICF for adults [27]. The difference between the ICF-CY and ICF is that, instead of the generic qualifiers from the adult ICF, the ICF-CY includes developmental aspects for children and young people [28]. The ICF contains in total 1,454 categories [7], while the ICF-CY contains 1,685 categories [27].

The linking methods used were developed by CIEZA *et al.* [29] as a set of 10 linking rules, with the objective of systematising the connection between the ICF and the clinical, technical and instrumental measures of the state of health and clinical interventions or rehabilitation. The linking process was made by following three steps. First, two researchers trained with the ICF, independently, identified and extracted the key concepts from patients' records. The key concepts were defined as categories related to the components of the ICF [structures and body functions, activity and participation and contextual factors (personal and environmental)]. Thus, the key concepts were extracted considering aspects of functioning, disability and health.

At the second step, the extracted concepts of records were linked to the most specific ICF-CY category by two independent health professionals according to the linking rules [29]. To resolve disagreements between two health professionals, a third person trained in the linking rules was consulted. Table 1 shows an example of the process of linking between the information present in the medical records and ICF-CY of a child diagnosed with hemiplegic cerebral palsy.

Case 14	Date of birth: 05/03/1997				
Profe ssional	Description in medical record	ICF categorie			
Physician	Right hemiplegia	ICD – G81			
	Walk with a walker	d450 and			
		e1151			
	Right equinus foot	s75021			
Physical	Hypertonic in the right hemisphere	b735			
Therapist	Reduced muscle strength	b730			
	Needs help to stand up	d4104			
Speech	The child can stay seated	d4153			
Therapist	Do not walk	d450			
	Slow speech. Can say few words	d330			
	Can keep the mouth closed	s320			
	Can eat all food consistencies	e1100			
	Well understanding of the demands	d310			
Occupational	Can move from the prone position to the seated position	d4103			
Therapist	Hypertonic	b735			
	Difficulty to use the right hand during fines movements	d440			
	Feeds on himself	d550			
	Needs assistance with bathing and dressing	d510 and			
		d540			
Psychologist	Calm child	b1263			
	Do not speak, but can communicates with gestures	d330 and			
		d3350			
	Interested in play	d920			
	Patient with 7 years old, accompanyied by mother that	e310			
-	reports that the child had CP when he was born				
Social Worker	Patient studies in a special school	e5853			
	Do not walk.	d450			
	Speak few words.	d330			
Dieticians	Good diet	e1100			
	Eutrophic patient	b530			

Table 1 – Example of the linking process between the information contained in medical records and the ICF-CY  $\,$ 

# d) Scoring the records

The researchers extracted 27 items from the medical records (9 related to body functions, 1 related to body structure, 12 related to activity and participation and 5 related to environmental factors) considered as essentials for the assessment by any professional involved in rehabilitation process.

The items were chosen by two researchers after analysis of the overall content of the assessments of all professions. A system's score was developed intending to

evaluate the information described in the medical records. Thus, three subscales were established: 1) Functioning, 2) Disability and 3) Environmental Factors. Each positive aspect related to functioning (structures, functions and capabilities preserved) was awarded one point (total score = 22). Each negative aspect described in connection with a disability (impairment, limitations or restrictions) earned one point (total score = 22). The description of each environmental factor in medical records was scored with one point (total score = 5). Inconsistent descriptions were identified in two cases (case 37 and case 40). In these cases, one professional reported that mental functions (case 37) and urinary functions (case 40) were impaired, while according to another professional, these functions, these items were not scored for these cases, but these information are described in the Table 6, with the signal +/-.

## e) Statistical methods

Descriptive analysis was used to describe the results. The documented frequency of categories and the mean, standard deviation and range of the number of records were calculated. All data was entered twice to avoid errors on data entry. SPSS 17.0 for Windows was used for analysis. Analysis of effect size [30] were conducted to verify if there is statistical differences in the number of Disability and Functionality scores reported by the professionals. Cohen's *d* lower than 0.20 indicates that non-effect was found; scores between 0.20 and 0.40 indicates a small effect, Cohen's *d* between 0.40 and 0.80 indicates a moderate effect and scores higher than 0.80 indicates a high effect. Based on the result of the effect size, the statistical power was calculated [31].

#### Ethical Considerations

The present study was approved by the Ethics Committee at the Universidade Federal de Minas Gerais (Parecer nº, ETIC 0257.0.203.000-10).

## **Results:**

We identified 81 items in the medical records related to the evaluation performed by the different professions involved with neuro-rehabilitation. The components involved in the evaluation process were body structure (15 categories), body functions (32 categories), activity and participation (24 categories) and environmental factors (10 categories). Speaking (d330) was the item most often described by professionals (ST, OT, PT, PSY, SW, PHY). Table 2 shows the items of interest in each work area during the evaluation of cases of cerebral palsy according to the ICF components.

In the area of physical therapy, was found the highest recorded number of different categories related to the process of functional evaluation (PT = 41, OT = 38, ST = 25, PSY=18, PHY=15, SW= 8, NT=7 items). Physical therapy and occupational therapy had the same number of items related to body function (OT =17, PT =17, ST = 11, PSY=9, PHY=5, NT=4, SW= 2 items). Physical therapy was the area that register

ed the highest number of evaluated items related to body structures (PT = 13, OT = 5, PHY=5, ST = 4, NT=1, PSY=0, SW= 0 items). Occupational therapy showed the greatest level of interest in component of activity and participation (OT = 15, PT = 9, PSY=7, ST = 6, PHY=3, SW= 3, NT=1 items). With regard to environmental factors, speech therapists presented the highest number of items (ST = 4, SW= 3, PT = 2, PHY=2, PSY=2, OT = 1, NT=1 item[s]).

## **INSERT TABLE 2 ABOUT HERE (PAGE 156)**

Table 3 presents the ICF chapters covered by at least one subcategory of the second level of the ICF for each professional field. Speech therapy and occupational therapy were the areas with the largest numbers of ICF chapters covered by at least one ICF subcategory (ST = 11, OT = 11, PT = 10, PSY=8, SW= 6, PHY=5, NT=3 chapters).

#### **INSERT TABLE 3 ABOUT HERE (PAGE 158)**

The results of the evaluation for the items covered by the professional rehabilitation service assessment for each case are shown in Table 4 for hemiplegic cerebral palsy (HCP), Table 5 for diplegic cerebral palsy (DCP) and Table 6 for quadriplegic cerebral palsy (QCP). The mean total score was 7.64 (SD= 2.81; range= 10) for the HCP cases; 7.27 (sd=2.32; range= 10) for the DCP cases, and 8.86 (sd=2.79; range= 9) for the QCP cases. Taking into account the reported disability score, higher scores were presented for the QCP cases (mean=5.13; sd=1.68), followed by the DCP cases (mean= 4.45; sd=2.01). The lowest disability scores were presented by the HCP cases (mean=3.78; sd=1.47). Considering the reported Functioning Scores, the best results were demonstrated by the HCP cases (mean=2.14; sd=1.46); intermediate results were presented by DCP children (mean= 1.27; sd=1.48) and the lowest functionality was reported for the QCP cases (mean =1.26; sd=1.37). Another important component assessed was the reported environmental factor score, for which the QCP cases presented the highest results (mean=2.46; sd=1.35), followed by the DCP cases (mean=1.54; sd=2.68); the HCP cases presented the lowest scores (mean=1.50; sd=1.01).

Analysing the scores reported for all cases considered together, not separated for the subtype of CP, the mean score for Disability was 4.45 (sd=1.73), while the total mean scores for Functioning was 1.55 (sd=1.44). Effect size analysis were conducted to

verify the magnitude of this difference and a Cohen's d =1.77 was obtained, which means a high effect size [30]. Considering the high effect size of 1.77 and the sample size of 40 participants, the statistical power obtained for this comparison was 99% [31].

## INSERT TABLES 4, 5 AND 6 ABOUT HERE (PAGES 73,74 AND 75)

The fourteen categories that have a minimum frequency of 40% during the registration process for HCP, DCP or QCP are presented in Table 7. Six categories showed the minimum frequency of 40% in all three motors conditions (temperament and personality\_ functions, swallowing, weight maintenance, speaking, walking and assistive products and technology for personal use in daily living).

## **INSERT TABLE 7 ABOUT HERE (PAGE 76)**

# Discussion

The key to successful treatment and prevention, in rehabilitation of chronic conditions, is to understand the relationship between impairments of structures and body functions, limitations in activities, restrictions on participation and psychosocial factors to define and select target problems that will be addressed by healthcare services [8]. For this reason, during rehabilitation planning, professionals must identify and record the positive and negative aspects related to the functioning of children with CP.

In this study, we observed that there was a major focus on the items related to body structures and body functions. This result was also emphasised by other studies that evaluated the goals for therapy and rehabilitation interventions [17, 20]. This

evidence suggests the need for ICF training for rehabilitation professionals, showing the relevance of other information related to functionality, such as activity, participation and environmental factors. Several studies have reported the relevance of training on the ICF for professionals involved with the rehabilitation process [6, 9-11]. Practitioners reported the need for more specific training and education on the use of the ICF for CP and the importance of applying scientific knowledge in clinical practice. Saleh et al. [20] identified a wide variety of responses from professionals about the procedures necessary for assessment and intervention. This lack of standardisation suggests the need for clinical guidelines to standardise the language among practitioners of rehabilitation and to update practitioners with the tools and best practices developed through clinical research. These clinical guidelines should follow the ICF as a reference for the biopsychosocial evaluation proposed by WHO and the deployment of expanded clinical services as a strategy for the humanisation of care.

The highest score related to the record of the environmental factors for children with quadriplegia (QCP) compared to the children with HCP and DCP suggests the need for greater support (facilitators) for the functioning of these cases. Similar results were found in the study by Andrade *et al.* [23] who identified statistical differences related to the increased presence of specific environmental factors for rehabilitation of children with neurological disorders when compared with controls.

The results of this study suggest that the information in the records is not standardized on the number and frequency of categories documented. Moreover, despite the same number of items documented in some cases (e.g. cases 33 and 34

presented both five categories recorded) there was observed a variation in the area of categories recorded. There are redundant descriptions for some items (see table 1, case 14, item d330, speaking was reported by speech therapist, psychologist and social worker) and relevant components of functioning for CP were not covered by the interdisciplinary evaluation. There is a need to define competencies through a consensus for evaluation and registration of the functional characteristics of children with CP to avoid redundant actions that are not properly integrated. This consensus could start from the set of codes that presented the highest frequencies in the records of the professionals involved with the rehabilitation. The use of the ICF code sets as a reference for evaluation can avoid the duplication of records and the omission of relevant information.

It is important to note that the Disability score was considerably higher than the Functioning score, with a high effect size. In general, practitioners recorded the negative aspects of functioning but did not describe the positive aspects (functions and capabilities that were preserved). Failure to register the lack of a roadmap for evaluation suggests that certain aspects of functioning have not been evaluated by the interdisciplinary rehabilitation team. It is important to formulate a list of items for the description of problems, as well as the body structures and body functions preserved and the level of performance and capacity necessary to develop a particular indicator of functional development. The evaluation of the positive aspects is important for the deep knowledge of children's skills. This practice is an alternative to implement the biopsychosocial model proposed by WHO. The ICF deconstructs the idea of linearity and dependence between impairment and limitation, proposing a multidirectional model, in which an individual may present an impairment without

functional limitation, or, on the other hand, it is possible that a limitation may not be associated with an impairment [7, 23, 27]. Thus, professionals also need to deconstruct the linear dependence between impairment and limitation or restriction in their clinical practice. For this, is needed a break of old paradigms for the implementation of the biopsychosocial model in the clinical practice, making it not just a theoretical model. The use of an ICF code sets for CP, based on the items obtained by health professionals involved in clinical practice, can contribute to the practical implementation of the multidirectional ICF model.

However, for the purposes of patient referrals from one professional to another (physical therapy to psychology, for example) the binary decision [32] related to the presence or absence of the positive or negative aspect could make the screening process faster and more comprehensive once the decision for referral is dichotomous; i.e., the patient needs or does not need care. That binary decision should be driven by ICF core sets.

ICF core sets can be used as reference by the rehabilitation team to systematise the assessment of functioning [25, 33]. The study developed by Koskinen *et al.* [34] used the ICF checklist to evaluate patients' medical documents in cases of brain injury. This study suggests the use of ICF core sets to better characterise the patients. However, there are no studies using ICF core sets to assess the quality of the rehabilitation records. The ICF checklist was not utilised by this study as in Koskinen *et al.*'s [34] study because this list of items does not include relevant categories for cases of CP, such as ingestion functions (b510), control of voluntary movement

functions (b760), gait pattern functions (b770), transferring oneself (d420), hand and arm use (d445) and caring for body parts (d520).

No study has developed a method of evaluation of medical records utilising the ICF as a reference. The method employed in this study may serve as an example for assessing the coverage of the records of the rehabilitation team according to the WHO biopsychosocial perspective. However, the definition of ICF core sets for CP is necessary to identify items that should comprise the interdisciplinary health assessment. The items raised by this study will constitute the body of a checklist for evaluating the functioning of CP. Studies are necessary to validate assessment content for interdisciplinary neuro-rehabilitation services. Considering that the ICF's operationalisation is still a challenge, an interdisciplinary validated core sets will make the application of the ICF more feasible during clinical practice in rehabilitation services. The results of the present study, along with the one developed by Schiariti *et al.* [24] - which identified the contents of quality of life measures for CP - and the study conducted by de Oliveira-Andrade *et al.* [35] - which presented the multidisciplinary perspective for the CP assessment using the ICF as reference - may integrate the set of preliminary studies to define future ICF core sets for CP.

Some difficulties limit the use of the ICF in the clinical practice, mainly related to the complexity and high number of items of the ICF. A challenge reported to the definition of ICF core sets was the difficulty of selecting a small number of categories to enable the use of ICF core sets in a condition with great variability and complexity such as stroke [25]. The total number of items identified in the records (81 categories) could be an indicator of feasibility for the amount of categories that

should comprise a standardised interdisciplinary evaluation for CP. There is not a consensus about the ideal number of items to include in the comprehensive ICF core set; numbers range from 55 for osteoarthritis [33] up to 130 items for stroke [25]. The fourteen items that had a minimum frequency of 40% for one of the three motors conditions of this study may serve as a reference for a brief core sets for CP. This short list could be used by the interdisciplinary rehabilitation team, since it shows items related to different professions (e.g. evaluation of temperament and personality, attributions of psychology; problems with weight maintenance, refer to dieticians; dysfunction of swallowing and speaking limitation, require the evaluation of speech therapy).

A limitation of the present study could be that it was carried out in only one rehabilitation centre. However, the aim of our study was to investigate the comprehensiveness of the assessment records of the interdisciplinary team (seven professional areas) as a pilot for future developing an ICF code sets for triage of cerebral palsy. It is worthwhile to consider that the Rehabilitation Centre in which this study was conducted assists a large population from a region of low Human Developmental Index. There is a high number of patients to be treated in this service and a small number of professionals who are qualified to provide appropriate care. Probably, the workload and a lack of a training program may have contributed to not having a systematic and standardized assessment in the rehabilitation service.

An alternative to making the use of the ICF more feasible in the clinical practice might be to develop an electronic medical record based on an ICF code sets. Some studies have already begun the process of computerising the assessment, as the ICF model [36, 37]. This is a trend that rehabilitation professionals should be aware of for updates and to improve their work process. This computerising tool could systematise the assessment and make the process of collecting and retrieving information more efficient and reliable. This step must be performed after an interdisciplinary content validation. For the development of electronic medical records based on the ICF as reference other actions are needed. The required steps are: 1) to develop training for professionals on the model of the ICF-CY; 2) to establish clinical guidelines on the items for the assessment of CP; 3) to develop an algorithm for the formulation of the electronic medical records and 4) to test the applicability of electronic records developed and its acceptability by professionals. The description of patient information as an electronic medical record is a strategy that needs to be developed to facilitate the collection and recovery of patient data.

The present study identified ICF categories that can help in organizing the evaluation and registration of information in the records of cases of CP. The content of the information involves categories related to the structures and body functions, activities and environmental factors. The information follows a heterogeneous pattern in content and number of categories. The most frequent items can comprise a ICF code sets for triage of CP. It is necessary to establish an interdisciplinary consensus based on ICF-CY for systematize the information's records.

# References

1- Driscoll MC. Creative technological aids for the learning-disabled child: an interdisciplinary project. Am J Occup Ther 1975;29:102-105.

2- Ellenor GL, Zimmerman S, Kriz J. An interdisciplinary approach to the dental care of the mentally disabled. J Am Dent Assoc 1978;97:491-495.

3- Gulmans J, Vollenbroek-Hutten MM, Van Gemert-Pijnen JE, Van Harten WH. Evaluating quality of patient care communication in integrated care settings: a mixed method approach. Int J Qual Health Care 2007;19: 281–288.

4- Dougherty NJ. A review of cerebral palsy for the oral health professional. Dent Clin North Am 2009;53:329-338.

5- Bilbao A, Kennedy C, Chatterji S, Ustün B, Barquero JL, Barth JT. The ICF: Applications of the WHO model of functioning, disability and health to brain injury rehabilitation. NeuroRehabilitation 2003;18:239-250.

6- Martinuzzi A, Salghetti A, Betto S, Russo E, Leonardi M, Raggi A, et al. The International Classification of Functioning Disability and Health, version for children and youth as a roadmap for projecting and programming rehabilitation in a neuropaediatric hospital unit. J Rehabil Med 2010;42:49-55.

7- World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.

8- Stucki G. International Classification of Functioning, Disability, and Health (ICF): A promising framework and classification for rehabilitation medicine. Am J Phys Med Rehabil 2005;84:733-740.

9- Allan CM, Campbell WN, Guptill CA, Stephenson FF, Campbell KE. A conceptual model for interprofessional education: The international classification of functioning, disability and health (ICF). J Interprof Care 2006;20:235-245.

10- Stephenson R, Richardson B. Building an interprofessional curriculum framework for health: A paradigm for health function. Adv Health Sci Educ Theory Pract 2008;13:547-557.

11- Tempest S, Mcintyre A. Using the ICF to clarify team roles and demonstrate clinical reasoning in stroke rehabilitation. Disabil Rehabil 2006;28:663-637.

12- Stucki G, Melvin J. The International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of physical and rehabilitation medicine. J Rehabil Med 2007;39:286-292.

13- Palisano RJ. A collaborative model of service delivery for children with movement disorders: A framework for evidence-based decision making. Phys Ther 2006;86:1295-1305.

14 – Steiner WA, Ryser L, Huber E, Uebelhart D, Aeschlimann A, Stucki G. Use of the model as a clinical problem-solving tool in physical therapy and rehabilitation medicine. Phys Ther 2002;82:1098-1107.

15- Rentsch HP, Bucher P, Dommen Nyffeler I, Wolf C, Hefti H, Fluri E, et al. The implementation of the 'International Classification of Functioning, Disability and Health' (ICF) in daily practice of neurorehabilitation: an interdisciplinary project at the Kantonsspital of Lucerne, Switzerland. Disabil Rehabil 2003;25:411-421.

16- Siebes RC, Ketelaar M, Gorter JW, Wijnroks L, De Blécourt AC, Reinders-Messelink HA, et al. Transparency and tuning of rehabilitation care for children with cerebral palsy: a multiple case study in five children with complex needs. Dev Neurorehabil 2007;10:193-204.

17- Nijhuis BJ, Reinders-Messelink HA, de Blécourt AC, Boonstra AM, Calamé EH, Groothoff JW, et al. Goal setting in Dutch paediatric rehabilitation. Are the needs and principal problems of children with cerebral palsy integrated into their rehabilitation goals? Clin Rehabil 2008;22:348-363.

18- Ustün TB, Chatterji S, Kostansjek N, Bickenbach J. WHO's ICF and functional status information in health records. Health Care Financ Rev 2003;24:77-88.

19- lezzoni LI, Greenberg MS. Capturing and classifying functional status information in administrative databases. Health Care Financ 2003;24:61-76.

20- Saleh MN, Korner-Bitensky N, Snider L, Malouin F, Mazer B, Kennedy E, et al. Actual vs. best practices for young children with cerebral palsy: a survey of paediatric occupational therapists and physical therapists in Quebec, Canada. Dev Neurorehabil 2008;11:60-80.

21 - Farias N, Buchalla, CSA. Classificação Internacional de Funcionalidade, Incapacidade e Saúde da Organização Mundial da Saúde: conceitos, usos e perspectivas. [The international classification of functioning, disability and health: concepts, uses and perspectives.] Rev Bras Epidemiol 2005;8:187-193 (in Portuguese).

22- Andrade PMO, Ferreira, FO, Haase, VG. O uso da CIF através do trabalho interdisciplinar no AVC pediátrico: relato de caso. [The use of the International Classification of Functioning, Disability and Health (ICF-WHO) in interdisciplinary care of stroke in childhood: Case report]. Contextos Clínicos 2009;2: 27-39 (in Portuguese).

23 – Andrade PMO, Ferreira FO, Lima EP, Vasconcelos AG, Haase VG. Cognitive profile, motor deficits and influence of facilitators for rehabilitation for children with neurological dysfunction. Rev Paul Pediatr 2011; 29(3): 320-327.

24- Schiariti V, Fayed N, Cieza A, Klassen A, O'donnell M. Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning. Disabil Rehabil 2011; 33:1330-1339.

25 – Geyh S, Cieza A, Schouten J, Dickson H, Frommelt P, Omar Z, et al. ICF core sets for stroke. J Rehab Med 2004;Suppl 44:135-141.

26 - Human Development Report 2010. The Real Wealth of Nations: Pathways to Human Development. Published for the United Nations Development Programme (UNDP). New York, 2010.

27- World Health Organization: International classification of functioning, disability, and health. Children and Youth Version ICF-CY. World Health Organization Switzerland, Geneva; 2007.

28- Riva S, Bullinger M, Amann E, von Mackensen S. Content comparison of haemophilia specific patient-rated outcome measures with the international classification of functioning, disability and health (ICF, ICF-CY). Health Qual Life Outcomes. 2010;8: 139.

29 - Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustün B, Stucki G. ICF linking rules: an update based on lessons learned. J Rehabil Med 2005;37: 212-218.

30- Cohen, J. A Power Primer. Psychological Bulletin, 1; 155-159, 1992.

31- Portney, LG; Watkins, MP. Foundations of Clinical Research: Applications to Practice. Prentice Hall, 2008.

32 - Kronk RA, Ogonowski JA, Rice CN, Feldman HM. Reliability in assigning ICF codes to children with special health care needs using a developmentally structured interview. Disabil Rehabil 2005;27: 977-983.

33 – Dreinhöfer K, Stucki G, Ewert T, Huber E, Ebenbichler G, Gutenbrunner C, et al. ICF core sets for osteoarthritis. J Rehab Med 2004;Suppl. 44: 75-80.

34- Koskinen S, Hokkinen EM, Sarajuuri J, Alaranta H. Applicability of the ICF checklist to traumatically brain-injured patients in post-acute rehabilitation settings. J Rehabil Med 2007;39:467-472.

35- de Oliveira-Andrade PM, de Oliveira-Ferreira F, Haase VG. Multidisciplinary perspective for cerebral palsy assessment after an International, Classification of Functioning, Disability and Health training. Dev Neurorehabil 2011; 14:199-207.

36- Spreyermann R, Lüthi H, Michel F, Baumberger ME, Wirz M, Mäder M. Longterm follow-up of patients with spinal cord injury with a new ICF-based tool. Spinal Cord 2011;49:230-235.

37 - Mayo NE, Poissant L, Ahmed S, Finch L, Higgins J, Salbach NM, et al. Incorporating the International Classification of Functioning, Disability, and Health (ICF) into an electronic health record to create indicators of function: proof of concept using the SF-12. J Am Med Inform Assoc 2004;11:514-522.
Code	Category/CP case	01	02	03	04	05	06	07	08	09	10	11	12	13	14	%
																category
1.1	M (1E )															reported
DI	Mental Functions	+	+	+									+	-		35.71
b110 b126	Consciousness															0.00
0120	nersonality					-			-	-	-	-		-	+	30.00
	functions															
b210	Seeing functions															0.00
b230	Hearing functions															0.00
b440	Respiratory									-						7.14
0110	functions															,
b5105	Swallowing	+	-	-	-		+					+		+		50.00
b530	Weight			+		+	-	+			+		-	-	+	57.14
	maintenance															
b620	Urinary functions															0.00
s7401	Joints of pelvic			-				-								14.28
	region															
d1	Learning and									-						7.14
	applying															
	knowledge															
d310	Receiving spoken						+			+	-				+	28.57
	messages															
d330	Speaking	+	-	-	-		-	-		-		+	+	+	-	78.57
d4153	M aintaining a			-			-							+		21.42
14154	sitting position															7.1.4
d4154	Maintaining a										-					7.14
1450	standing position															95 71
d430	Warking (capacity)	-	-	-	+	+	-			-	-	-	+	+	-	63.71
d540	Dressing	-	-			_						-	-	-	-	42.85
d550	Fating	-	+			-						_	-	+	+	35 71
d7	Internersonal									_	_				1	14.28
u/	interactions and									_	_					14.20
	relationships															
d820	School education					-										7.14
d9	Community. social										-				+	7.14
	and civic life															
e1100	Food				*						*	*	*		*	35.71
e1101	Drugs										*	*				14.28
e1151	Assistive products	*	*	*	*		*	*	*		*		*	*	*	78.57
	and technology for															
	personal use in															
	daily living															
e310	Immediate family	ļ										*		*	*	21.42
e5800	Health services			0.7												0.00
Reporte	d Disability Score	03	04	05	02	03	04	02	01	06	06	04	04	05	04	
Reporte	d Functioning	03	02	02	01	02	02	01	00	01	01	02	03	05	05	
Score	d En vinon mandal	01	01	01	02	00	01	01	01	00	02	02	02	02	02	
<b>Keporte</b>	su environmental	01	01	01	02	00	01	01	01	00	03	03	02	02	03	
Tactors	Score	07	07	00	05	05	00	05	02	07	10	00	00	10	10	
1 Julai S	LUIC	07	07	00	05	05	09	05	02	07	10	09	09	12	12	

Table 4 - Items described in the records of cases of hemiplegic cerebral palsy.

Disabilities (impairments. limitations or restrictions)
+ Functioning (structures. functions. performance or capabilities preserved)
\* Environmental factor reported.

Code	Category/CP case	15	16	17	18	19	20	21	22	23	24	25	%
													category
													reported
b1	Mental functions												0.00
b110	Consciousness												0.00
b126	Temperament and		-		-	-	-		-	-	+		63.63
	personality												
1010	functions												26.26
6210	Seeing functions		-				-	-			-		36.36
b230	Hearing functions												0.00
6440	Respiratory												0.00
15105	functions												45.45
05105	Swallowing	-				-			-	+	+		45.45
6530	Weight	-		-		-	-				-		45.45
h620	Infinitenance												0.00
0020	Utiliary functions							-					9.09
\$7401	region				-								0.00
d1	Learning and		-				-						18.18
	applying												
	knowledge												
d310	Receiving spoken		+					+		+			27.27
1000	messages												01.01
d330	Speaking	-	-	-		-	-	-	-	+	-		81.81
d4153	M aintaining a sitting position	-				-	+						18.18
d4154	M aintaining a												0.00
	standing position												
d450	Walking	-	+	-	-	-	-	-	-	-	-		90.90
d510	Washing oneself		-					-					18.18
d540	Dressing		-				+	-					27.27
d550	Eating		+	-	-		+	-					45.45
d7	Interpersonal												0.00
	interactions and												
	relationships												
d820	School education				+						-		18.18
d9	Community. social and civic life						+						9.09
e1100	Food		*			*		*			*		36.36
e1101	Drugs												0.00
e1151	Assistive products	*	*	*	*		*	*	*				63.63
	and technology for												
	personal use in												
	daily living												
e310	Immediate family					*			*	*	*	*	45.45
e5800	Health services					*							9.09
Reporte	ed Disability Score	05	06	04	04	06	06	07	04	02	05	00	
Reporte	Reported Functioning		03	00	01	00	04	01	00	03	02	00	
Score	Score												
Reporte	Reported Environmental		02	01	01	03	01	02	02	01	02	01	
Factors	Factors S core												
Total So	core	06	11	05	06	09	11	10	06	06	09	01	

Table 5 - Items described in the records of cases of diplegic cerebral palsy.

Disabilities (impairments. limitations or restrictions)
+ Functioning (structures. functions. performance or capabilities preserved)
\* Environmental factor reported.

Code	Category/CP case	26	27	28	29	30	31	32	33	34	35	36	37	38	39	40	%
																	category
																	reported
b1	Mental Functions		-									-	-/+			-	26.66
b110	Consciousness								+								6.66
b126	Temperament and	-	-	-							-	-	-	-		-	53.33
1.010	personality functions																20.00
b210	Seeing functions		-					-				-					20.00
b230	Hearing functions		+									+	-				20.00
b440	Respiratory functions					-					+				-		20.00
b5105	Swallowing	-	+		-			+		+	+						40.00
b530	Weight maintenance	+	+	-			-		+			-		-		+	53.33
b620	Urinary functions		-									-			-	-/+	26.66
s/401	Joints of the pelvic				-	-	-	-	-	-	-						46.66
d1	region	-															0.00
aı	centring and																0.00
1210	Applying knowledge																12.22
u310	messages		+								+						15.55
4330	Speaking	_	_	_		_	_				_	_		_		_	80.00
d4153	Maintaining a sitting	-	-	-		-	-	+	-	-	-	-	+	+	_	+	93.33
u+155	position																75.55
d4154	Maintaining a			-							-		-	-	-		33 33
u	standing position																00.00
d450	Walking	-	-	-	-	-	-	-	-	-		-		-		-	80.00
d510	Washing oneself		-													-	13.33
d540	Dressing		-													-	13.33
d550	Eating																0.00
d7	Interpersonal																0.00
	interactions and																
	relationships																
d820	School education										-						6.66
d9	Community, social		+														6.66
	and civic life																
e1100	Food	*		*	*		*	*		*	*	*	*		*	*	73.33
e1101	Drugs	*		*	*						*	*			*		40.00
e1151	Assistive products	*				*					*	*	*	*	*	*	53.33
	and technology for																
	personal use in daily																
a210	IIVINg	*		*	*	*	*	*				*	*	*		*	66.66
e510	Health services	*										*		*			12 22
Banarte	d Disability Score	05	00	06	05	05	04	04	03	03	06	08	04	05	04	06	15.55
Doporte	d Functioning Score	03	09	00	00	00	04	04	03	03	00	01	04	0.0	04	00	
Reporte	d Environmental	01	00	00	00	00	00	02	02	01	03	01	01	01	00	02	
Factors	Score	05	00	05	05	02	02	02	00	01	05	04	05	05	05	05	
Total Sc	ore	11	14	00	08	07	06	08	05	05	12	13	08	00	07	11	
		11	14	09	00	07	00	00	05	05	12	13	00	09	07	11	

Table 6 - Items described in the records of cases of quadriplegic cerebral palsy.

- Disabilities (impairments, limitations or restrictions)
- + Functioning (structures, functions, performance or capabilities preserved)
- \* Environmental factor reported.

Code	Category	Hemiplegia	Diplegia	Quadriplegia
		(% category	(% category	(% category
		reported)	reported)	reported)
b126	Temperament and	4 (50.00)	3 (63.63)	5 (53.33)
	personality			
	functions*			
b5105	S wallowing*	4 (50.00)	4 (45.45)	7 (40.00)
b530	Weight	3 (57.14)	4 (45.45)	5 (53.33)
	maintenance*			
s7401	Joints of the pelvic	14.28	0.00	6 (46.66)
	region			
d330	Speaking*	2 (78.57)	2 (81.81)	2 (80.00)
d4153	M aintaining a	21.42	18.18	1 (93.33)
	sitting position			
d450	Walking*	1 (85.71)	1 (90.90)	2 (80.00)
d510	Washing oneself	5 (42.85)	18.18	13.33
d540	Dressing	5 (42.85)	27.27	13.33
d550	Eating	35.71	4 (45.45)	0.00
e1100	Food	35.71	36.36	3 (73.33)
e1101	Drugs	14.28	0.00	7 (40.00)
e1151	Assistive products	2 (78.57)	3 (63.63)	5 (53.33)
	and technology for			
	personal use in daily living*			
e310	Immediate family	21.42	45.45	4 (66.66)

\*The categories with a minimum frequency above 40% for both HCP, DCP, and QCP are highlighted in bold.

Table 7 - Categories that presented a minimum frequency of 40% during the registration process for HCP, DCP or QCP.

#### 4.3 ESTUDO 3: MULTIDISCIPLINARY PERSPECTIVE FOR CEREBRAL PALSY ASSESSMENT AFTER AN INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH TRAINING

**Referência:** de Oliveira Andrade PM, de Oliveira Ferreira F, Haase VG. Multidisciplinary perspective for cerebral palsy assessment after an International, Classification of Functioning, Disability and Health training. *Dev Neurorehabil* 2011; 14(4):199-207.

#### Abstract:

**Objective:** To assess knowledge related to the ICF before and after an ICF training and to identify items to compose monocentric rehabilitation ICF code set for cerebral palsy (CP). Methods: a) Design: A cross-sectional study with a descriptiveexplorative design. b) Participants: professionals from the fields of physiotherapy, nutrition, dentistry, occupational therapy, psychology, social work, speech therapy and medicine.c) Instrument: a questionnaire to assess ICF's knowledge (total score=17). *Results:* A high effect size of the ICF training was found (Cohen's d=4.10). Ninety-one and 43 ICF categories were selected for a comprehensive evaluation and triage, respectively, for CP. *Conclusion:* ICF categories were identified to compose a comprehensive evaluation and for triage through a ICF code sets for CP. Studies are needed to validate the instrument on the knowledge of the ICF and to test the impact of ICF's training for clinical rehabilitation of CP.

**Keywords:** WHO's ICF knowledge, cerebral palsy, multidisciplinary, rehabilitation code set, training program

### Introduction

Cerebral palsy (CP) is a disease that demands action by teamwork of professionals with different backgrounds [1]. A major challenge for professionals in the rehabilitation field is the establishment of a uniform language among professionals [2]. Satisfactory communication is an important component in the success of a team [3-5]. There is a lack of integration among the main problems and needs of children with CP to the objectives set by the rehabilitation professionals [6,7]. The lack of communication and integration affect the transparency of the rehabilitation process [6]. The difficulty reported by Nijhuis *et al* [7] was related to poor documentation of information related to the assessment and definition of therapeutic goals. The lacks of a systematic documentation and according to the needs of patients affect the users of rehabilitation services. The limitation on communication may impair the humanization of care and make impossible the viability of a service according to the biopsychosocial approach endorsed by the World Health Organization -WHO [8].

The International Classification of Functioning, Disability and Health (ICF) intend to improve communication between health professionals and systematise the assessment of functioning through use of the biopsychosocial model [8]. Rentsch *et a.l* [9] and Tempest and Mcintyre [10] used the ICF to organise and divide professional responsibilities in a rehabilitation service in Switzerland and England, respectively. The division of tasks can improve the efficiency of rehabilitation services.

The literature describes various difficulties and challenges to the operationalisation of the ICF in clinical rehabilitative practice [11, 12]. The main difficulties are related to complexity, size, and the time-consuming nature of clinical application [13]. The ICF contains in total 1,454 categories [8] while the ICF-CY contains 1,685 items [14]. The 'ICF has been developed as a reference classification and is not intended to be a practical tool' [15]. Therefore, methodological approaches to make the ICF model suitable for clinical practice, must be developed to make the WHO biopsychosocial model used in clinical rehabilitation.

Attempts to improve the feasibility of applying the ICF for clinical practice have led to the development of the ICF checklist and ICF core sets [16]. Moreover, to make better known the ICF, there is a need to train health professionals. A training program on the ICF for professionals was developed in Italy [17-19] Sweden [20] and Mozambique [21]. These trainings are necessary because professionals are not familiar with the terminology and the model proposed by the WHO through the ICF. Saleh *et al* [22] highlights the need to encourage knowledge dissemination regarding current best practice and the need for more training and education for use in clinical practice.

A literature review identified the limited use of the ICF in developing countries [23]. Of the 243 studies examined, only 6 (2.5%) were conducted by authors from developing countries. Most of the authors of these studies (50%) are from Germany and the USA [23]. This evidence strengthens the argument of the need for greater efforts by governments, researchers and health professionals from developing countries intending to improve the adherence to guidelines for ICF use. To expand the use of ICF by rehabilitation services, it will be necessary for a teamwork to validate the content of the tools used for assessment. The health professionals that participate in the validation must understand the concepts, terminology, model, structure and coding strategies of functioning and disability according to the WHO biopsychosocial perspective. Validation by the appropriate health teams or services is necessary for an assessment to proceed in an integrated fashion and reflect the reality of services and different profiles of health professionals who compose the health team. This strategy can be an alternative for implementing the biopsychosocial model in different rehabilitation services through a multidisciplinary approach. Considering the low use of ICF in health services from developing countries [23], the difficulty of implementing this classification in clinical rehabilitation [13] and the lack of standardized assessments of children with CP [24,25] the objectives of this study were: 1) to identify the knowledge of professionals from a rehabilitation service about the terminology and structure of the ICF and 2) to identify the relevant ICF code set for CP from the perspective of a multidisciplinary teamwork.

### Methods:

The study was conducted in two steps: 1) identification of the items that should comprise a multidisciplinary assessment of CP functioning from the perspective of a rehabilitation service team before training with regard to the ICF; 2) identification of the items that should comprise a multidisciplinary assessment of CP functioning from the perspective of a rehabilitation service team after ICF training. Figure 1 shows the study's steps.

### **INSERT FIGURE 1 (PAGE 97)**

### 1- First Step:

All professionals involved with the rehabilitation of children diagnosed with CP at the Centre for Rehabilitation of Diamantina – Brazil were invited to participate. Participation in the first stage of the study included 18 professionals from different areas, including nutrition, physical therapy, occupational therapy, medicine, dentistry, social work, speech therapy and psychology. Table I shows the professionals' characteristics.

n = 18	Frequency	Mean	Standard Deviation	Range
Age (years) Females %	77.8%	30.2	5.9	22
Time of graduation (months)		74.5	69.4	276
Complete	83.4%			
Experience with CP (months)		28.3	20.2	60
Working time in rehabilitation unit (months)		33.1	17	54

Table I. Characteristics of the Center for Rehabilitation professionals.

The professionals were asked to answer a semi-structured questionnaire, including questions about a) the assessment of CP functioning, b) professionals' self-reported ICF knowledge, and c) the relevance of this classification for the evaluation process. The content described by professionals was linked with ICF through ICF linking rules [26].

### 2 – Second Step

Six professionals participated in the second stage of the study. These professionals were from the Centre for Rehabilitation and experts in the areas of nutrition, physical therapy, occupational therapy and psychology. The second stage of the study consisted of four steps, as follows: a) tests on ICF knowledge, b) in-service training in ICF, c) selection of ICF items with which to assess CP functioning through use of a structured questionnaire, and d) retest of ICF knowledge.

### a) Test of ICF knowledge

Participants were asked to answer the 'Questionnaire to assess ICF's knowledge' with 15 objective questions, including 14 questions with 5 alternatives (a b, c, d, and e) and one question (question 15) with three parts requesting an answer of true or false. Each correct answer to the questions with five alternatives was scored one point. In Question 15, the correct answer for each part was scored as one point. Therefore, question 15 was worth a maximum score of three points. Thus, the maximum total assessment score for the *Test on ICF Knowledge* was 17 points. The questions were related to terminology (impairment, limitations, and restrictions), concepts (capacity and performance), model (biopsychosocial and multidimensional), history (date of approval by WHO) and composition (components, number of levels and chapters) of the ICF [27].

### b) In-service training in ICF

ICF training was divided into three modules lasting three hours. The content of Module I comprised the history, concepts, and structure of the ICF model. Module II presented the methods for development of the ICF core sets and the ICF checklist. Module III involved the performance of a practical activity. During this last training module, participants linked the ICF to the answers that they had provided in the semi-structured questionnaire conducted in the first step of the study.

c) Strategy to identify ICF items to assess CP functioning - Structured Questionnaire

The professionals selected the items that they considered to be relevant to the triage and to the comprehensive assessment for CP. The structured questionnaire comprised items identified in the results of the semi-structured questionnaire (Step 1) and the ICF checklist [28]. The items were presented to the professionals so that they could identify relevant items that should compose a comprehensive evaluation for CP, as well as items that were indispensable for the triage of these cases.

### d) Retest of ICF knowledge

The *Test on ICF Knowledge* used before the ICF training was applied again, to assess the assimilation of the information provided during ICF training.

### Statistical analysis

Descriptive analyses were conducted to describe the mean scores of the reported items to comprise the triage and the comprehensive assessment before and after the ICF training.

The effect size (Cohen's d) [29] was calculated to verify the differences with regard to ICF knowledge before and after the ICF training. Cohen's d lower than 0.20 indicated that no effect was found; scores between 0.20 and 0.40 indicated a small effect, Cohen's d between 0.40 and 0.80 indicated a moderate effect and scores higher than 0.80 indicated a high effect.

### Ethical Considerations

The present study was approved by the Ethics Committee (ETIC 0257.0.203.000-10).

### Results

1- Self-perceptions reported by health professionals

Table II shows the results from professionals' self-reports related to knowledge of the

ICF, the importance of an ICF training program and relevance of a consensus on the

set of items for assessing CP functioning.

Table II. ICF knowledge, training program and a consensus for CP evaluation - self-reported.

			E	G	R	В	VB
Professionals'		self-	5.6%	0%	44.4%	22.2%	27.8%
reported know	ledge						
			VI	1	U	l don'i	t know
Importance o	f repo	orted	72.2%	11.1%	0%	16.	.7%
in-service train	ing in I	ICF					
			VI		1		U
Importance	of	а	100%		0%		0%
consensus							

E=excellent - G = good - R= regular - B= bad - VB = very bad

VI = Very important - I = Important - U = Unimportant

## 2-Measuring ICF knowledge

The mean score related to the *Test on ICF's* Knowledge before the training was 6 points (SD 1.1, range 5-10 points). Major errors were found related to employment of the correct terminology (questions 1, 2 and 3) and understanding of the biopsychosocial model (question 15). After the ICF training, the mean score was 11.7 points (SD 1.6, range 10-14 points). A high effect size of the ICF training was found (Cohen's d = 4.10).

3- Evaluation of cerebral palsy functioning

a) Items reported

Table III shows the number of relevant items reportedly used by the professionals surveyed to assess CP functioning. Physical therapy and occupational therapy were the areas that reported the highest number of relevant items that should comprise the functioning assessment for CP cases (25 and 15 items, respectively), whereas nutrition and dentistry reported the smallest number of items (5 items). The mean number of items reported was 12 (SD 8.36).

Table III. Number of ICF codes reported by professionals through use of a semistructured questionnaire.

ICF	SW	ΡΤ	ST	ОТ	DT	PSY	NT	PHY
b	0	11	8	8	1	4	2	6
S	0	4	0	0	0	0	0	0
d	3	8	1	6	3	6	0	2
е	5	2	0	1	1	0	3	0
Т	8	25	9	15	5	10	5	8

s= body structures, b= body functions, d= activity and participation, e= environmental factors, SW= social workers, PT = physical therapist, ST = speech therapist, OT = occupational therapist, DT= dentistry, PSY = psychologists, NT= nutrition, PHY = physician

### b) Selected Items

At this stage, participants were invited to mark, in a structured questionnaire based on second-level ICF categories, those items that they considered to be relevant to a comprehensive assessment of CP functioning. Table IV shows the number of items selected by the professionals for a comprehensive evaluation of CP functioning. Physical therapists and occupational therapists selected the highest number of items to comprise the assessment (57 and 42 items, respectively), whereas the nutritionists reported the smallest number of items (8 items). The mean number of selected items was 35.6 (SD 17.92).

ICF	PT	ОТ	DT	PSY	NT
b	29	13	14	21	5
S	10	3	2	0	0
d	15	22	11	13	0
е	3	4	5	5	3
Т	57	42	32	39	8

Table IV. Number of ICF items selected by professionals through structured questionnaire.

s= body structures, b= body functions, d= activity and participation, e= environmental factors, PT = physical therapist, OT = occupational therapist, DT = dentistry, PSY = psychologists, NT= nutrition

After the ICF training, the mean of the reported item that should comprise the CP assessment increased, with a high effect size (Cohen's d=1.69). In the semistructured questionnaire, 54 items in the first-, second- and third-level ICF categories for evaluating CP functioning (s = 3, b = 26, d = 17 and e = 8) were described by at least one professional. In the structured questionnaire, 91 items in the first-, second- and third-level ICF categories (b = 40 categories, s = 8 categories, d = 32 categories, and e = 11) were selected by at least one professional for the comprehensive evaluation of CP. Considering the triage of CP, 43 ICF categories were selected (categories b = 24, d = 17 categories, and e = 2 categories) by the professionals. Table V presents the items described before the training and selected after training on the ICF.

Table V. ICF categories described (Questionnaire I) and ICF codes selected (Questionnaire II). by professionals for CP functioning evaluation and codes for screening in a rehabilitation service (PHY = physician, PT = physical therapist, ST = speech therapist, OT = occupational therapist, PSY = psychologists, SW= social workers, NT= nutrition , DT = dentistry).

CODE	CATEGORY	QUESTIONN AIRE I Items selected before ICF training	QUESTIONN ARE II COMPREHENSIVE SET Items selected after the ICF training	QUESTIONN ARE II SET FOR SCREENING
S	BODY STRUCTURES			
s320	Structure of mouth (atresia palate)	PT	PT, DT	
s4	Structures of the cardiovascular, immunological and		DT	
\$7	Structures related to movement	DT		
s710	Structure of head and peck region		PT	
\$7201	Joints of shoulder region		PT OT	
s730	Structure of upper extremity		PT. OT	
s7401	Joints of pelvic region	PT	PT	
s750	Structure of low er extremities		PT	
s760	Structure of Trunk		PT	
s Total		3	8	0
b	BODY FUNCTIONS			
b1	Mental functions	PT, PSY, OT	PT, PSY, OT	PT
b110	Consciousness functions	, ,	PT, PSY	
b114	Orientation functions		PT, OT, PSY, DT	DT
b117	Intelellectual functions	DT	PT, OT, PSY, DT	OT
b1301	Motivation	PSY	PSY	
b134	Sleep functions		PSY	
b140	Attention functions		PSY	
b144	Memory functions		PSY	
b152	Emotional functions	PSY	PT, PSY	PT
b156	Perceptual functions		PT, PSY	
b164	Higher-level cognitive functions		PT, PSY, DT	57
b167	Mental functions of language	PI, SI	PI	PI
b2	Sensory functions and pain	SI, OI		
D210	Seeing functions			
D230	Hearing functions	PHI		
b200	Vestibular function of balance	DT		
b2331	Functions of the cardiovascular haematological	NT PHY	DT	11,101
b410	immunological and respiratory systems			
b410 b420	Blood pressure functions			DT
b420	Haematological system functions			PT
b435			0 PSY	PSY
b430	Respiration functions	PT ST	PT DT	PT
b5	Functions of the digestive, metabolic and endocrine	, 01	NT	
	systems			
b510	Ingestion functions	PT, ST		
b5100	Sugar	ST	PT, DT	PT
b5102	Chew	ST	PT, DT	PT
b5105	Sw allow ing	PT, ST	PT, NT, DT	PT, NT
b515	Digestive functions		NT	NT
b525	Defecation functions	PHY	PSY, NT	NT
b530	Weight maintenance functions	NI	PI, PSY	
b620		PHY	PSY	
D640	Sexual functions	OT DEV	PSI NT DEV DT	
b660	Neuromus culos kelet and movement-related	ST PHY OT	NI, PST, DI	
57	functions	51, 111, 01		
b710	Mobility of joint functions	PT, OT	PT, OT	PT
b730	Muscle power functions	PT, OT	PT, OT	PT 5T
b/35	Muscle tone functions	PI, OT		
b7602	Control of voluntary movement functions			
b765	Involuntary movement functions	01		
b703	Gait pattern functions	рт	Г I, UI <b>рт</b>	F I
b770	Functions of the skin and related structures	11	PT	
b Total		26	40	24
S TOLAI		20	70	<b>4</b> 7

d	ACTIVITIES AND PARTICIPATION	SW, FT and DT		
d115	Listenig		DT	
d140	Learning to read		PSY	
d3	Communication	DT		
d310	Communicating with – receiving – spoken messages	PT	PT, DT	PT
d315	Communicating with – receiving – non-verbal		PT, PSY, DT, OT	PT
	messages			
d330	Speaking	PT, ST, TO, PSY,	PT, PSY, DT, OT	PT
		PHY		
d350	Conversation		PT	
d410	Changing basic body position	PT	PT, OT	PT
d4103	Sit	OT	OT	
d420	Transferring oneself	PT	PT, OT	
d430	Lifting and carrying objects		PT, OT	OT
d440	Fine hand use	PT , OT	PT, OT	PT
d445	Hand and arm use	OT	PT, OT	
d450	Walking	PT, PSY, OT	PT, PSY, OT	
d465	Moving around using equipment		PT, OT	PT, OT
d470	Using transportation		PT	
d510	Washing oneself	PHY	PT, PSY, DT, OT	OT
d520	Caring for body parts		PT, PSY, OT	OT
d5201	Dental care	DT	DT	DT
d540	Dressing		OT	OT
d550	Eating		OT, DT	OT
d560	Drinking		OT	OT
d570	Looking after one's health		PSY	
d620	Acquiring a place to live		OT	OT
d630	Preparing meals		OT	OT
d640	Doing housew ork		PSY, OT	PSY, OT
d710	Basic interpersonal interactions		PSY, DT	
d740	Formal relationships	PSY	PSY	
d750	Informal social relationships	PSY	PSY	
d760	Family relationships	PSY	PSY	
d820	School education	SW, PSI, OT	PSY, OT	
d860	Basic economic transactions		OT	OT
d9	Community, social and civic life	PT		
d920	Recreation and leisure		PSY	
940	Human rights	SW		
d Total		17	32	17
е	ENVIRONMENTAL FACTORS			
e1100	Food	DT, NT	DT, NT	
e1101	Drugs	PT, NT, OT	PT, NT, PSY, DT,	
	-		OT	
e115	Products and technology for personal use in daily		PT, OT	
	living			
e1151	Products and assistive technology for personal use	PT	PT	PT
	in daily life			
e165	Assets	SW, NT	NT	
e310	Immediate family	SW	PSY, DT, OT	
e320	Friends		PSY	
e340	Personal care providers and personal assistants		PSY	
e355	Health professionals		PSY	
e360	Health-related professionals			~
e410	individual attitudes of immediate family members	014/	טו, טר	01
e525	Housing services, systems and policies	SW		
e575	General social support services, systems and	SW		
-500		014/		
6580	mealth services, systems and policies	5₩		6
e Total		8	11	2
Total		54	91	43
General				

### Discussion:

Recent studies show the importance of using the ICF during the home care [30] and functional assessment of HIV in Brazil and South Africa [31]. On the other hand, the present study identified that health professionals involved in a rehabilitation service possessed limited knowledge about the ICF, both according to their self-reported knowledge and according to a test designed to evaluate their knowledge. This evidence may be associated with the completion time of undergraduate education (mean of 6 years) and the relatively recent publication of the ICF in Portuguese [27]. Even those that graduated after publication of the ICF in Portuguese may not have had classes about this classification, considering the lack of knowledge exhibited by the teaching staff. Considering the need to deploy the ICF model, this study provides an example of possible implementation of ICF in health services. Obviously, other services can use other deployment strategies, but this study can be used as an example for the beginning of this process of professional training for clinical rehabilitation. The involvement of health professionals and services in implementing the ICF can close the gap between research about ICF and clinical practice. The lack of guidelines for assessment makes information management and teamwork difficult.

A strong effect of size was observed when comparing the ICF knowledge results before and after the ICF training, indicating an improvement in ICF knowledge after training. Furthermore, an increase in the number of items reported to comprise the CP assessment was observed after ICF training, which may indicate that the professionals began to identify other items that should comprise a comprehensive assessment, according to the biopsychosocial model. The World Health Organization and the researchers involved in construction of the ICF core sets emphasise the relevance of the participation of professionals with different backgrounds (medicine, physiotherapy, occupational therapy, psychology, social work and sociology) from different countries in the construction of the ICF core sets [32,33]. However, the methods employed in the preliminary studies (systematic review delphi exercise and focus groups) should be complemented with studies performed by a multidisciplinary team involved in health services from different countries [34-36]. This could contribute to the understanding of ICF application in the context of rehabilitation, especially in developing countries [37,38]. The use of these studies could be an innovation at conferences for the definition service that should be utilised for support of the ICF core sets. This alternative would still minimise the difficulties related to defining the optimal number of items for the composition of core sets [32].

The use of ICF in developing countries is limited, compared to its use in developed countries [23]. The only study that reported the completion of ICF training in a third-world country was the one conducted by Borgnolo *et al.* [21] The implementation of the ICF in health services represents a long-term project, even in developed countries such as Sweden [39]. This study represents an alternative implementation of the ICF in a public rehabilitation service. The steps followed by this study may be followed or adapted by other health services that seek to introduce the ICF in clinical practice.

A medical record study not yet published [40] shows that the assessment of professionals in cases of CP in a rehabilitation centre in a developing country is not

integrated. The information is disorganised and lacks the coverage of the ICF perspective. An assessment with specific items and mainly common items represents a strategy to transform a service conducted by a multidisciplinary service approach to an interdisciplinary or even transdisciplinary undertaking. The present study has shown common and specific aspects of the professions involved in the rehabilitation process. This observation reinforces the idea that professions have specificities and overlaps in their approaches in rehabilitation services.

The use of the ICF by the rehabilitation team will require ongoing training of the professionals involved with the evaluation and outcome because the tools and application methods are constantly under development by researchers. This training program should be promoted by governments, as seen in Italy [17-19]. If there is no ICF training the assessments of functioning can not be systematised, as in the ICF model, and ICF terms (impairment, limitation and restriction) can be misused or used as synonyms.

A limitation of this study was the loss of professionals in the second step of the study. Some professionals participated only in the description of items considered to be relevant to assessing CP functioning. A possible reason for a lack of full membership is that many professionals were working up to three jobs, at up to 60 hours weekly. On the other hand, there were representatives from the areas of physiotherapy, occupational therapy, nutrition, dentistry and psychology at every step of the study. Considering the great complexity of interdisciplinary work involving members of two professions, the complexity is even greater when eight occupations are involved. Therefore, clinical guidelines are needed to guide the process of evaluation in a multidisciplinary rehabilitation service. These clinical guidelines can be conducted after ICF's training for all professionals of rehabilitation.

The effect size estimate yields accurate results because it allows an interpretation that is in line with clinical effect. The small sample did not allow the realization of a statistical test to evaluate the statistical significance of training on the ICF. However, the study aimed to identify the contents of the assessment before and after training on the ICF. Therefore, further studies are needed to investigate the significance of training on the ICF to the knowledge of professionals involved with the clinical rehabilitation.

This study represents a step towards the incorporation of an integrated assessment that adheres to the WHO biopsychosocial perspective in evaluating the public rehabilitation service of a developing country such as Brazil. Other actions are needed such as developing an electronic medical record to facilitate the registration and retrieval of information and develop ICF core sets for CP.

In contrast to the Rentsch *et al.* [8] study, this investigation sought to assess the extent of professionals' knowledge about the ICF and their participation in the selection of ICF items for evaluation of ICF CP, after an ICF training programme. The study developed by Rentsch *et al.* [8] defined the roles of professionals in a rehabilitation service, involving ICF activity and participation chapters. In the present study, the items of the assessment were described and selected after training on the ICF.

The present study is a preliminary study to define an ICF code set that can be used to assess CP functioning. These CP ICF code sets could be used in the construction of future core sets for CP. Studies are needed to validate the instrument used to test ICF knowledge. Future researches should be conducted to assess the long-term impact on the participants' ICF knowledge and to verify possible changes in clinical practice of professionals who participated in the training process.

Declaration of Interest: The authors report no conflicts of interests. The authors

alone are responsible for the content and writing of the paper.

### **References:**

1. Nijhuis BJ, Reinders-Messelink HA, de Blécourt AC, Olijve WG, Haga N, Groothoff JW *et al.* Towards integrated paediatric services in the Netherlands: a survey of views and policies on collaboration in the care for children with cerebral palsy. Child: Care, Health and Development 2007;33:593-603.

2. Choi BC, Pak AW. Multidisciplinarity, interdisciplinarity, and transdisciplinarity in health research, services, education and policy: 2. Promotors, barriers, and strategies of enhancement. Clinical and Investigative Medicine 2007;30:224-32.

3. Allan CM, Campbell WN, Guptill CA, Stephenson FF, Campbell KE. A conceptual model for interprofessional education: The international classification of functioning, disability and health (ICF). Journal of Interprofessional Care 2006;20:235-45.

4. Vyt A. Interprofessional and transdisciplinary teamwork in health care. Diabetes/metabolism research and reviews 2008;24:106-9.

5. Rice K, Zwarenstein M, Conn LG, Kenaszchuk C, Russell A, Reeves S. An intervention to improve interprofessional collaboration and communications: a comparative qualitative study. Journal of Interprofessional Care 2010;24:350-61.

6. Siebes RC, Ketelaar M, Gorter JW, Wijnroks L, De Blécourt AC, Reinders-Messelink HA, Van Schie PE, Vermeer A. Transparency and tuning of rehabilitation care for children with cerebral palsy: a multiple case study in five children with complex needs. Developmental Neurorehabilitation 2007;10:193-204

7. Nijhuis BJ, Reinders-Messelink HA, de Blécourt AC, Boonstra AM, Calamé EH, Groothoff JW *et al.* Goal setting in Dutch paediatric rehabilitation. Are the needs and principal problems of children with cerebral palsy integrated into their rehabilitation goals? Clinical Rehabilitation 2008;22:348-63

8. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.

9. Rentsch HP, Bucher P, Dommen Nyffeler I, Wolf C, Hefti H, Fluri E *et al.* The implementation of the 'International Classification of Functioning, Disability and Health' (ICF) in daily practice of neurorehabilitation: an interdisciplinary project at the Kantonsspital of Lucerne, Switzerland. Disability and Rehabilitation 2003; 25:411-21.

10. Tempest S, Mcintyre A. Using the ICF to clarify team roles and demonstrate clinical reasoning in stroke rehabilitation. Disability and Rehabilitation 2006;28:663-7.

11. Schuntermann MF. The implementation of the International Classification of Functioning, Disability and Health in Germany: experiences and problems. International Journal of Rehabilitation Research 2005;28:93-102.

12. Maini M, Nocentini U, Prevedini A, Giardini A, Muscolo E. An Italian experience in the ICF implementation in rehabilitation: preliminary theoretical and practical considerations. Disability and Rehabilitation 2008;30:1146-52.

13. Rauch A, Cieza A, Stucki G. How to apply the International Classification of Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. European Journal of Physical and Rehabilitation Medicine 2008;44:329-42.

14. World Health Organization. International Classification of Functioning, Disability, and Health – version for children & youth: ICF-CY. WHO Workgroup for development of version of ICF for Children & Youth. Geneva: World Health Organization; 2007.

15. Stucki G, Kostanjsek N, Ustün B, Cieza A. ICF-based classification and measurement of functioning. European Journal of Physical and Rehabilitation Medicine 2008; 44:315-28.

16. Ustün B, Chatterji S, Kostanjsek N. Comments from WHO for the Journal of Rehabilitation Medicine Special Supplement on ICF Core Sets. Journal of Rehabilitation Medicine 2004;I:7-8.

17. Leonardi M, Bickenbach J, Raggi A, Sala M, Guzzon P, Valsecchi MR *et al.* Training on the International Classification of Functioning, Disability and Health (ICF): the ICF-DIN Basic and the ICF-DIN Advanced Course developed by the Disability Italian Network. The Journal of Headache and Pain 2005;6:159-64.

18. Reed GM, Dilfer K, Bufka LF, Scherer MJ, Kotzé P, Tshivhase M *et al.* Three model curricula for teaching clinicians to use the ICF. Disability and Rehabilitation 2008;30:927-41.

19. Francescutti C, Fusaro G, Leonardi M, Martinuzzi A, Sala M, Russo E *et al.* Italian ICF training programs: describing and promoting human functioning and research. Disability and Rehabilitation 2009;31:46-9. 20. Pless M, Ibragimova N, Adolfsson M, Björck-Akesson E, Granlund M. Evaluation of in-service training in using the ICF and ICF version for children and youth. Journal of Rehabilitation Medicine 2009;41:451-8.

21. Borgnolo G, Soares IC, dos Santos Soares B, Gongolo F, Vaz P, Meucci P *et al*. Preliminary results of ICF dissemination in primary health care in Mozambique: sharing the Italian experience. Disability and Rehabilitation 2009;31:78-82.

22. Saleh MN, Korner-Bitensky N, Snider L, Malouin F, Mazer B, Kennedy E, Roy MA. Actual vs. best practices for young children with cerebral palsy: a survey of paediatric occupational therapists and physical therapists in Quebec, Canada. Developmental Neurorehabilitation 2008;11:60-80.

23. Jelsma J. Use of the International Classification of Functioning, Disability and Health: A literature survey. Journal of Rehabilitation Medicine 2009;41:1–12.

24. Andrade PMO, Ferreira FO, Vasconcelos AG, Lima EP, Haase VG. Perfil cognitivo, déficits motores e influência dos facilitadores para reabilitação para crianças com disfunções neurológicas. Revista Paulista de Pediatria 2011;29: in press (in Portuguese).

25. Shevell MI, Majnemer A, Poulin C, Law M. Stability of motor impairment in children with cerebral palsy. Developmental Medicine and Child Neurology 2008;50:211-5.

26. Cieza A, Geyh S, Chatterji S, Kostanjsek N, Ustün B, Stucki G. ICF linking rules: an update based on lessons learned. Journal of Rehabilitation Medicine 2005;37:212-18.

27. Organização Mundial de Saúde – OMS; Organização Panamericana de Saúde - OPAS. (2003). *Classificação internacional de funcionalidade, incapacidade e saúde*. São Paulo - SP: Universidade de São Paulo, 2003.

28. World Health Organization. *ICF Checklist Version 2.1a, Clinical Form for International Classification of Functioning, Disability and Health: ICF*. Geneva: WHO; 2001.

29. Cohen J. Quantitative methods in psychology: A power prime. *Psychological Bulletin* 1992; 112:155-9.

30. Martins EF, de Sousa PH, de Araujo Barbosa PH, de Menezes LT, Souza Costa A. A Brazilian experience to describe functioning and disability profiles provided by combined use of ICD and ICF in chronic stroke patients at home-care. Disability and Rehabilitation 2011 [Epub ahead of print]

31. Myezwa H, Buchalla CM, Jelsma J, Stewart A. HIV/AIDS: use of the ICF in Brazil and South Africa--comparative data from four cross-sectional studies. Physiotherapy 2011;97:17-25.

32. Geyh S, Cieza A, Schouten J, Dickson H, Frommelt P, Omar Z, et al. ICF core sets for stroke. Journal of Rehabilitation Medicine 2004;44:135-41.

33. Coenen M, Cieza A, Freeman J, Khan F, Miller D, Weise A *et al.* The development of ICF Core Sets for multiple sclerosis: results of the International Consensus Conference. Journal of Neurology 2011; [Epub ahead of print]

34. Verhoef J, Toussaint PJ, Putter H, Zwetsloot-Schonk JH, Vliet Vlieland TP. The impact of introducing an ICF-based rehabilitation tool on staff satisfaction with multidisciplinary team care in rheumatology: an exploratory study. Clinical Rehabilitation 2008;22:23-37.

35. Salghetti AM, Betto S, Russo E, Petacchi E, Pradal M, Martinuzzi A. Projecting and programming rehabilitation based on ICF-CY format in a neuropediatric hospital unit. Disability and Rehabilitation 2009;31:55-60.

36. Martinuzzi A, Salghetti A, Betto S, Russo E, Leonardi M, Raggi A *et al.* The International Classification of Functioning Disability and Health, version for children and youth as a roadmap for projecting and programming rehabilitation in a neuropaediatric hospital unit. Journal of Rehabilitation Medicine 2010;42:49-55.

37. Alhajj T, Wang L, Wheeler K, Zhao W, Sun Y, Stallones L *et al.* Prevalence of disability among adolescents and adults in rural China. Disability and Health Journal 2010;3:282-8.

38. Vanleit B. Using the ICF to address needs of people with disabilities in international development: Cambodian case study. Disability and Rehabilitation 2008;30:991-8.

39. Björck-Åkesson E, Wilder J, Granlund M, Pless M, Simeonsson R, Adolfsson M *et al.* The International Classification of Functioning, Disability and Health and the version for children and youth as a tool in child habilitation/early childhood intervention--feasibility and usefulness as a common language and frame of reference for practice. Disability and Rehabilitation 2010;32: 125-38.

40. Andrade PMO, Ferreira FO, Mendonça AP, Haase VG. Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. Disability and Rehabilitation (in press).



Figure 1: Study steps

# 4.4 ESTUDO 4: IS THE CAPACITY CONSTRUCT FROM INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH USED IN EMPIRICAL STUDIES OF CEREBRAL PALSY?

### ABSTRACT

Our purpose was check if the use of the term capacity is consistent with the definition of International Classification of Functioning, Disability and Health, based on a review of original articles of cerebral palsy cases. Empirical research studies were identified according to the following six stages: 1) Identification phase; 2) Exclusion phase; 3) Reading of abstracts; 4) Identification of constructs related with activities and participation (capacity, capability, or performance); 5) Analysis of complete articles; and 6) Analysis of the methods used to the capacity assessment. We identified 66 publications, of which 33 were empirical studies. 30.3% used terms related to the capacity, capability, or performance in their abstracts and 21.2% used the term capacity. The concept of capacity was not employed according to the directions of the International Classification of Functioning, Disability and Health. The definition of capacity needs a narrow definition. A theoretical and methodological debate is necessary for a consensual approach.

**KEYWORDS:** cerebral palsy, International Classification of Functioning, Disability and Health, ICF, activities, capacity

### Introduction

There is an important debate for rehabilitation of people with disabilities about the difficulties in measuring some constructs of the International Classification of Functioning, Disability and Health.<sup>1,2,3</sup> This discussion is related to conceptual and methodological issues that need improvement to facilitate an assessment of functioning of children with neurological disorders such as cerebral palsy.

"Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorder of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems".<sup>4</sup> This chronic disease results in impairments in the structures and functions of the body, leading to limitations in activities and restrictions in participation<sup>5-8</sup>, which can affect the functional performance and capacity of individuals with this condition. A consensus on the rehabilitation of children with cerebral palsy is necessary to ensure that the needs of this population are addressed in accordance with scientific evidence, as well as to reduce the variability of the actions of professionals in the face of subjective interpretations and lack of knowledge.9 One problem found in the literature has to do with the lack of a consensus related to the concepts of capacity, capability and performance for investigation of activity and participation for cerebral palsy.<sup>2</sup> The concepts of capacity and capability are used without distinction<sup>10-12</sup> despite the methodological and theoretical differences between these constructs. These differences make comparisons between studies difficult, with a clinically heterogeneous approach prevailing. The World Report on Disabilities<sup>13</sup> recommends the use of the International Classification of Functioning, Disability and Health as a reference for evaluation of children with cerebral palsy.

Nodenfelt<sup>3</sup> criticised the concept of capacity in the International Classification of Functioning, Disability and Health. Nodenfelt's commentary gave rise to a debate about that construct<sup>14-19</sup>. Further, critical studies are necessary to investigate the use of the constructs of capacity in the literature. Other qualifiers for the assessment of activity and participation in the literature available are the constructs of performance<sup>14</sup> and capability.<sup>2,20</sup> The study by Holsbeeke et al<sup>2</sup> is the only empirical study that investigated capacity, capability, and performance. The descriptions of the constructs of capacity and performance, as defined by the World Health Organization<sup>21</sup> and by Holsbeeke et al<sup>2</sup>, are shown in Table 1.

Table 1 – Concepts	of capacity,	capability,	and	performance	defined	by	the	World
Health Organization <sup>21</sup>	and by Hols	beeke et al <sup>2</sup>						

Construct	Capacity	Capability	Performance
WHO, 2001 <sup>21</sup> and WHO, 2007 <sup>27</sup>	Execution tasks in a standard environmental	Not addressed by the International Classification of Functioning, Disability and Health	Execution tasks in a current environmental
Holsbeeke et al, 2009 <sup>2</sup>	Can do in a standardized, controlled environment	Can do in daily environment	Does do in daily environment

The International Classification of Functioning, Disability and Health by the World Health Organization aimed "*to provide an unified and standard language and framework for the description of health and health-related states*" (p. 3, World Health Organization, 2001).<sup>21</sup> Many authors have reported International Classification of Functioning, Disability and Health advances, reinforcing the relevance of this classification for the evaluation of cerebral palsy <sup>5,15,22</sup> or the analysis of evaluation

tools for this childhood neurological disorder.<sup>23,24</sup> On the other hand, because International Classification of Functioning, Disability and Health is a new classification method, several conceptual questions have been raised<sup>3,25,26</sup>, necessitating a critical debate on the classification<sup>14</sup>10 years after the approval by the World Health Organization.

Table 1 shows that the concept of capability was not addressed by the International Classification of Functioning, Disability and Health. This classification suggested that: *"Typically, the capacity qualifier without assistance is used in order to describe the individual's true ability which is not enhanced by an assistance device or personal assistance"* (page 230, World Health Organization, 2001).<sup>21</sup> This advice can be seen in one of the examples of the International Classification of Functioning, Disability and Health having to do with the interaction between the constructs of capacity and performance. In one of the examples, the International Classification of Functioning, Disability and Health suggests that an individual may:

"have capacity limitations without assistance, and no performance problems in the current environment (e.g., an individual with mobility limitations may be provided by society with assistive technology to move around)" (page 18, International Classification of Functioning, Disability and Health for Children and Youth).<sup>27</sup>

This advice agrees with the definition of standard environment or without assistance, but the use of assistance is allowed by International Classification of Functioning, Disability and Health for assessment of capacity. In this way, no clear direction for a standardized use is given in the International Classification of Functioning, Disability and Health. Without assistance, if the individual is not able to move from the bed to the living room without a walker, then this person presents a complete limitation in the activity of walking or a disability for this task. However, with the assistance of a walker, the individual is able to complete the task, and thus, a complete limitation on the completion of the task does not exist. In this case, performance (activity with aid) can be greater than capacity because with the aid, the task is completed, but without the aid, the task is not completed. Thus, the following three hypotheses may occur in the interaction between the constructs of capacity and performance, if we consider the concepts from the International Classification of Functioning, Disability and Health: 1) performance = capacity; 2) performance < capacity; 3) performance > capacity. The correct hypothesis for each functional activity depends on the interference of contextual factors. These three possibilities make it difficult to measure and interpret information relating capacity and performance. This complexity is highlighted by the following unanswered question: how can performance be greater than capacity if one considers that the International Classification of Functioning, Disability and Health defines capacity as "the highest probable level of functioning that a person may reach in a given domain at a given moment"?<sup>27</sup>

Considering clinical practice, what are the central questions for professionals involved with rehabilitation? Are these professionals evaluating capability, capacity, or performance? The lack of clarity of the conceptual and methodological problems of the constructs of the International Classification of Functioning, Disability and Health can affect its improvement and development. Considering the necessity of strengthening this debate, the aim of the present study was to review original articles that used the International Classification of Functioning, Disability and Health model to study cerebral palsy cases, analyzing the use of the terms capacity, capability and performance and to suggest a path to improving their clinical feasibility. Raising these questions may begin a debate on the practical applicability of the constructs of the International Classification of Functioning, Disability and Health with respect to the evaluation of activity and participation component.

### Methods

Empirical studies conducted with cerebral palsy cases, that used the International Classification of Functioning, Disability and Health model were selected. The inclusion of the studies in the review was based on an analysis of the title and abstract of the papers in meeting these eligibility criteria: empirical study with cerebral palsy cases, use of the International Classification of Functioning, Disability and Health model and use of at least one of these terms: capacity, capability or performance.

The search of the papers was conducted in the Pubmed/Medline database for the period from May 2001 to May 2011. Two reviewers (PMOA and FOF) independently screened the searched results and selected articles for closer scrutiny. The search for publications related to the use of the International Classification of Functioning, Disability and Health in empirical studies focusing on cerebral palsy went through the following six stages. *1) Identification phase:* The search terms used to identify the studies were ICF OR International Classification of Functioning, Disability and Health AND cerebral palsy. *2) Exclusion phase*: We excluded literature reviews and studies published in non-English languages and studies without an available abstract. The term "NOT review" was added in the search and limits for language and date were

activated. 3) Reading of abstracts: We read abstracts to exclude studies regarding literature reviews that had not been identified in the second phase, studies conducted only with health professionals, or papers that analysed evaluation instruments. 4) *Identification of constructs:* The fourth step was to identify the abstracts that used the terms capacity, capability, or performance. 5) *Analysis of the complete texts:* The complete texts for the studies identified in Stage 4 were analysed to identify the use of one or more terms being studied (capacity, capability, or performance) in the publication. 6) *Analysis of the methods used to the capacity assessment:* The final stage was to analyse the methods used in the study of capacity. The analysis of the methods related to the investigation of capacity was conducted by the identification of the instruments used in the study. The flow indicating the steps in the selection and analysis of the articles is shown in Figure 1.

### **INSERT FIGURE 1 ABOUT HERE (PAGE 124)**

#### **Results:**

Table 2 presents the results for the type and number of studies identified during the first phase of the study. In the first stage (identification phase) 33 empirical studies were identified for analysis.

Type of study	Number
Literature reviews	22
Tutorials	1
Publications in other languages	3
Publications prior to 2001	1
Studies with health professionals (physiotherapy and	4
occupational therapy)	
Studies of evaluation instruments	1
Abstract not available	1
Empirical Studies	33
Total	66

Table 2: Type and number of studies identified

Data accessed on 22/May/2011

Some studies associated the concepts of performance and capability as defined by Holsbeeke et al<sup>2</sup> and did not consider the concept of capacity as laid out by the International Classification of Functioning, Disability and Health.<sup>12,28</sup> In addition, there are studies that reported limitations in activities and restrictions on participation; however, there is not a clear description of the constructs evaluated.<sup>5,8</sup>

Various studies reported negative aspects relating to disability, such as limitations in activities and restrictions on participation<sup>5,6</sup>, but did not report positive aspects involved with functioning. The professionals involved in rehabilitation more frequently documented aspects of the disability and not functioning in the medical records of children with cerebral palsy.<sup>29</sup>

33 empirical studies were identified, ten of which (30.3%) used terms related to the constructs of capacity, capability, or performance in the abstract. These studies are shown in Table 3. The study by Beckgung and Hagberg<sup>5</sup> used the expression capacity in the abstract, but this term was not related to the study of activity or participation. All studies used the term performance, seven studies (21.2%) used the

capacity term, and one article used the term capability in the abstract and/or in main

text.

Table 3: Empirical studies that used the terms capacity, capability, or performance in the abstract

Study	Ν	Construct		
-	(CEREBRAL PALSY)	Capacity	Capability	Performance
Johnston & Wainwright	1			A-FT
(2011)				
Ketelaar et al (2010) <sup>12</sup>	94	A-FT	A-FT	A-FT
Tseng et al 2011 <sup>8</sup>	216	A-FT		A-FT
Hoare et al (2010) <sup>34</sup>	40	FT		A-FT
Mutlu et al (2010) <sup>38</sup>	448	A-FT		A-FT
Boyd et al (2010) <sup>36</sup>	52	A-FT		FT
Retarekar et al (2009) <sup>35</sup>	1	FT		A-FT
Nieuwenhuijsen et al (2009) <sup>31</sup>	87			A-FT
Law et al (2007) <sup>32</sup>	220			A-FT
Schenker et al (2006) <sup>33</sup>	148	FT		A-FT

A-FT= term found in the abstract and Full Text; FT=term found only in Full Text

The seven evaluation instruments employed in the searched studies are listed in Table 4.

Table 4: Evaluation instruments related to the use of the term capacity

Study	Evaluation instruments related to the use of the term capacity	Year of publication
Ketelaar et al (2010) <sup>12</sup>	Gross Motor Function Measure	1989
Hoare et al (2010) <sup>34</sup>	Quality of Upper Extremity Skills Test	1991
Tseng et al 2011 <sup>8</sup>	Paediatric Evaluation of Disability Inventory	1992
Mutlu et al (2010) <sup>38</sup>	Gross Motor Function Classification System	1997
	Manual Ability Classification System	2006
Boyd et al (2010) <sup>36</sup>	Melbourne Unilateral Upper Limb Assessment of Function	1999
Retarekar et al (2009) <sup>35</sup>	6-minute walk test	2002
Schenker et al (2006)	No report on evaluation of capacity through an instrument	

Tseng et al<sup>8</sup> evaluated questions related to daily capacity, which represents capability in accordance with Holsbeeke et al<sup>2</sup> and not capacity in accordance with the International Classification of Functioning, Disability and Health. This study reported that the constructs of capacity and performance were evaluated in accordance with the daily (real) functioning of the child. This is evidenced by the following sentence: *"both capacity and performance should be taken into account when assessing a child's daily function."*<sup>8</sup> Tseng *et al*<sup>8</sup> used the Paediatric Evaluation of Disability Inventory for the evaluation of capacity and performance. This instrument suggested that an interview should be conducted with parents or guardians and that the questions dealing with functional skills are related to performance and not capacity. The procedures for the study state that interviews were conducted at school, at the clinic, or by telephone. This method reinforces the idea that the activities were evaluated with regard to the real or daily environment as a reference and not with a standardised or controlled reference for functional tests or observation directly with the child.

Ketelaar et al<sup>12</sup> used the Gross Motor Function Measure-88 for the evaluation of capacity. This instrument allows the use of support, aids, and an orthosis (Sitting – Item 22: "Sit on mat, supported at thorax by therapist"). Standardisation of the presence of support for evaluation of capacity would contribute to greater clarity of the construct that is being investigated. Further, the study does not present a relation between the constructs of capacity, capability, and performance.

Hoare et al<sup>34</sup> evaluated capacity using the grasps component of the Quality of Upper Extremity Skills Test. The activity of grasping (d4401) is related to the fine control of

the hand (d440). The study presented the isolated objective of evaluating the activity of grasping to evaluate capacity. Other activities related to the fine hand use, such as taking (d4400), manipulating (d4402), and releasing (d4403), could comprise an evaluation battery for a more complete investigation of capacity related to the fine hand use. In addition, the study did not discuss the relation between capacity and performance for manual activities.

Retarekar et al<sup>35</sup> evaluated aerobic capacity, which is related to body functions (International Classification of Functioning, Disability and Health code, b4551). The study evaluated aerobic capacity by means of the 6-Minute Walk Test, a clinical measure of sub-maximal functional exercise capacity. In this study, the term of capacity was evaluated according to the directions of the International Classification of Functioning, Disability and Health (standard environment and higher level of functioning), but it was applied to the functions of tolerance to exercises (b455) and not to activities or participation.

The objective of the study by Boyd et al<sup>36</sup> was to evaluate different activities (manual, school, and occupational) after a rehabilitation program. This study used the Melbourne Unilateral Upper Limb Assessment of Function to evaluate capacity. The objective of this instrument is to evaluate performance by therapists over the long term [Royal Children's Hospital Melbourne]<sup>37</sup>. There was no evaluation or discussion of the relation between the constructs of capacity and performance in this study.
# **Discussion:**

With respect to the World Health Organization proposal to standardise language for health-related concepts, we observed that various studies did not use the construct of capacity as recommended by the International Classification of Functioning, Disability and Health, even though they cited this classification and this term. This may be related to the difficulty in operationalising the evaluation of this construct. The concept of capability not included in the International Classification of Functioning, Disability and Health<sup>20</sup> was only cited by Ketelaar et al<sup>12</sup>, although other studies used the daily environment as a reference in the evaluation of capacity. We noticed some incongruence between the concept of capacity and the direction of the International Classification of Functioning, Disability and Health regarding the method for measuring this construct. According to the International Classification of Functioning, Disability and Health, "the capacity qualifier describes an individual's ability to execute a task or an action and indicate the highest probable level of functioning that a person may reach in a given domain at a given moment."<sup>21</sup> The conceptual problem is the strategy recommended for capacity assessment. According to the International Classification of Functioning, Disability and Health, "to assess the full ability of the individual, one would need to have a standardised environmental to neutralise the varying impact of different environments on the ability of the individual."<sup>21</sup>. In other words, the International Classification of Functioning, Disability and Health determined that this contextual factor might be called a "uniform environment". This definition is justified by the importance of a standard or uniform environment allowing international comparison of data. But what is a standard or uniform environment? How can one define a uniform environment for different

activities? There is no definition of a standard environment or an environment with a uniform impact within the different categories of activity and participation in the International Classification of Functioning, Disability and Health. What would be a standard environment for the evaluation of daily activities, such as eating, washing clothes, brushing teeth, throwing out the trash, talking, and playing? What about interpersonal relations and interactions, such as relations between a child and a parent, romantic relations, and informal relations? Is a standard or uniform environment possible for these activities in different countries with cultural and socio-economic differences? One interpretation for the understanding of uniform environment is related to the administration of standardized tests (same equipment, for example). On the other hand, the concept of capacity could be applied in real situations (patient's home, for example).

The difficulties in operationalising the construct of capacity of the International Classification of Functioning, Disability and Health are apparent after an analysis of the instruments and definitions used in the studies. For the evaluation of capacity, we identified seven instruments. These instruments did not evaluate capacity as directed by the International Classification of Functioning, Disability and Health. Further, none of the instruments evaluated the constructs of capacity, capability, and performance for the same items or domains. This observation confirms the report by Holsbeeke et al<sup>2</sup>, which stated that there are no tools available for evaluating these constructs. The objective of the study by Mutlu et al<sup>38</sup> was to *"evaluate performance and capacity as defined by Gross Motor Function Classification System and Manual Ability Classification of Functioning, Disability and Health"*. The conceptual problem can be

seen in the objectives of Gross Motor Function Classification System and Manual Ability Classification System, which are instruments for evaluation of performance or capability and not capacity. These two instruments take into consideration the daily environment; therefore, they do not consider a standard or uniform across environments. Further, Manual Ability Classification System is a generic instrument that aims to identify manual skills that are related to different activities, such as tasks related to personal care and domestic life, as well as civic, social and community life. The lack of standardisation of tasks for the classification of manual skills makes it difficult to define a controlled or uniform environment for the evaluation of capacity. In this regard, the study by Mutlu et al<sup>38</sup> did not evaluate capacity as recommended by International Classification of Functioning, Disability and Health (in a the standardised environment). The two systems of classification used (Gross Motor Function Classification System and Manual Ability Classification System) allowed the use of support, assistance, and/or adapted equipment. The evaluation of the construct, according to the direction of the International Classification of Functioning, Disability and Health, leaves open the question of support assistance. These two possibilities, related to the presence of facilitators, lead to difficulties in standardising the use of the construct of capacity.

The studies that presented an objective of evaluating capacity in accordance with the directions International Classification of Functioning, Disability and Health did not follow its recommendations concerning the use of a standard environment for evaluation, with the absence of aid or support for the realisation of the activity, and the definition of capacity as a component of activity and participation and not for body functions. These observations suggest that new methodological proposals should be

prepared, or that instruments and procedures that already exist for the evaluation of functional capacity should be improved. Further, we did not find any empirical studies with a methodological proposal to improve the concept of capacity as proposed by the International Classification of Functioning, Disability and Health.

The capacity concept was also misused in the studies by Retarekar et al<sup>35</sup> and Meester-Delver et al<sup>42</sup>. The aerobic capacity, for example, is a body function component. Capacity is a qualifier for the component of activities and should not be extrapolated to the component of body function and structure. Thus, it is necessary to define the most appropriate terminology for any functioning component.

# New perspectives on evaluation of functional capacity and potential performance

No clear way for a standardized assessment of capacity was provided by the International Classification of Functioning, Disability and Health<sup>1</sup>. Considering the operational difficulties for the definition of a standard or uniform environment and the need for the use of support or aid to reach the functional limit in patients with neurological impairments, it is more viable to consider an ideal or desired environment during the evaluation of capacity. This satisfactory context could favour the promotion of functional capacity. The presence of a facilitator or opportunity (term suggested by Nordenfelt)<sup>3</sup> may aid in the achievement of capacity. The inclusion of facilitators and the elimination of barriers to functioning comprise the elements for an ideal or desired environment. Thus, the therapist should identify the ideal or desired environment for optimal functioning. The definition of an ideal environment is more

viable than the definition of a standard environment because the desired environment can vary depending on socio-economic and cultural characteristics. In addition, this environment is modified by the child's development over the course of years.<sup>39</sup>

The standard environment is a concept applied to the clinical environment and not to an environment that is real or possible for an individual. Further, the concept of the standard environment cannot be used in clinical practice for primary health care in home visits<sup>36</sup> because we cannot define a standard or controlled environment in the house of each patient; each residence has its own characteristics, and it is not possible to define a controlled, uniform or standard environment. However, it is possible to define an ideal or desired environment. This ideal environment could be defined by public health policies that guarantee access by individuals to this desired environment. The definition of the ideal environment may facilitate operational definitions for the measure of capacity. The International Classification of Functioning, Disability and Health states that capacity reflects "skill adjusted to the environment". In individuals with impairments, skill can be adjusted through rehabilitation strategies. However, in some cases, it is more viable to adjust the environment rather than to adjust skills.<sup>40</sup> For this reason, evaluation of capacity should take place after the manipulation of the environment so that the context is adjusted to the skills in order to reach maximum functioning. This environment needs to be adjusted according to the functional potentials of the individual. The elimination of barriers and the inclusion of facilitators can contribute to achieving maximal functioning or functional capacity.<sup>41</sup> Thus, the definition of a uniform or standard environment for the measurement of capacity is incongruent with the definition of capacity: "maximum level of functioning". This maximum level of functioning can only

be reached in an ideal or desired environment, not necessarily in a uniform or standardised environment. The concept of capability presented by Holsbeeke *et al*<sup>2</sup> identifies what an individual can accomplish in his real environment, not his ideal or desired environment. The concept of capability, which was not considered by the International Classification of Functioning, Disability and Health, is more appropriate than the concept of capacity for the evaluation of the potential performance of the individual. However, there is no prediction of the definition of an ideal or desired environment for the evaluation of capability. The definition of the ideal environment is relevant because the real environment will not always present facilitators for achieving optimal capability.

# Evaluation of potential performance: a necessary construct for rehabilitation professionals

Professionals involved with the rehabilitation process aim to identify abilities that have been preserved or compromised after an injury or disease.<sup>9</sup> In addition, these professionals should evaluate and document the potential performance of patients. Potential performance of an individual is related to abilities that are possible but are not exploited or trained by the individual. This construct is the difference between the capacity of an individual, considering the presence of facilitators for functioning (ideal environment), and the individual's actual performance. This potential performance can be influenced positively by facilitators or negatively by barriers or obstacles. The objective of professionals involved with rehabilitation should be to transform potential performance into real performance. For this reason, the study of this construct is relevant to the clinical approach of professionals involved in rehabilitation. The central question is the following: *What does the child not do that he could do after a* 

rehabilitation program? Awareness of potential performance and therapeutic planning that is centred on these non-explored skills can contribute to the effectiveness of rehabilitation and to the measurement of the impact of these actions. Some authors report that there is incongruence between the objectives defined by rehabilitation professionals and the objectives of parents or children with cerebral palsv.<sup>43</sup> If these objectives are defined in consensus, by taking into account potential performance, adherence by the child/family may increase, and thus, therapeutic interventions would be more effective. However, there is a need to develop evaluation instruments that address the constructs<sup>2</sup> and domains<sup>44</sup> related to the study of activity and participation. In addition, another debate initiated by Badley<sup>45</sup> concerning differences between activity and participation requires theoretical and methodological study in order to be implementable with regard to educational and clinical questions.<sup>46</sup> A training of health professionals on the terms and functioning model is necessary<sup>47</sup>. but the critical points of this classification needs to be mentioned and discussed for the improvement of conceptual and methodological issues of the International Classification of Functioning, Disability and Health. Table 5 presents a possible new perspective on the evaluation of functional capacity and potential performance.

Table 5: Proposal of a definition of functional capacity and potential performance as well as the contextual factors involved in these constructs

Construct	Definition	Personal Factors	Environment
Functional capacity	Ability to execute a task in an ideal environmental with maximal effort or motivation	Maximum disposition	ldeal, desired, adapted to needs
Potential performance	Task that the child does not do and could do	Lack of knowledge about capacity, lack of disposition towards the task, lack of skill	Not adapted or not exploited, existence of economic or others barriers. There's a shortage of facilitators

# **Final Considerations:**

There was a lack of consensus in the use of the terms related with activities and participation constructs capacity, capability and performance in the reviewed papers. Otherwise, these terms were not used in accordance to the International Classification of Functioning, Disability and Health definitions. To standardize the use of the concept of capacity, there is a need of a narrow definition of capacity.

An absence of clarity regarding the concept of standard environment in order to define capacity represents a barrier for the study of functional limits for children in accordance with their clinical and environmental reality. The term "uniform or standard environment" is better applied to measuring the body function component of the International Classification of Functioning, Disability and Health than it is to measuring activity and participation component, because the environment for developmental skills needs to be adjusted according to each child characteristics.

# DECLARATION OF CONFLITING INTEREST

The authors have no conflicts of interest to disclose with regard to this article.

#### REFERENCES

1. Whiteneck G, Dijkers MP. Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Arch Phys Med Rehabil*. 2009; 90(11 Suppl):S22-35.

2. Holsbeeke L, Ketelaar M, Schoemaker MM, Gorter JW. Capacity, capability, and performance: different constructs or three of a kind? *Arch Phys Med Rehabil.* 2009; 90(5):849-55.

3. Nordenfelt L. On health, ability and activity: comments on some basic notions in the ICF. *Disabil Rehabil*. 2006; 28(23):1461-5.

4. Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy April 2006. *Dev Med Child Neurol.* Suppl. 2007; 109:8–14.

5. Beckung, E, Hagberg, G. Neuroimpairments, activity limitations, and participation restrictions in children with cerebral palsy. *Dev Med Child Neurol.* 2002; 44(5): 309-16.

6. Chan HS, Lau PH, Fong KH, et al. Neuroimpairment, activity limitation, and participation restriction among children with cerebral palsy in Hong Kong. *Hong Kong Med J.* 2005; 11(5):342-50.

7. Wright FV, Rosenbaum PL, Goldsmith CH, et al. How do changes in body functions and structures, activity, and participation relate in children with cerebral palsy? *Dev Med Child Neurol.* 2008; 50(4):283-9.

8. Tseng MH, Chen KL, Shieh JY, et al. The determinants of daily function in children with cerebral palsy. *Res Dev Disabil.* 2011; 32(1):235-45.

9. Ferrari A, Cioni G; Società Italiana di Medicina Fisica e Rehabilitativa-Società Italiana di Neuropsichiatria dell'Infanzia e dell'Adolescenza (SIMFER-SINPIA) Intersociety Commission. Guidelines for rehabilitation of children with cerebral palsy. *Eura Medicophys.* 2005; 41(3):243-60.

10. Tieman BL, Palisano RJ, Gracely EJ, Rosenbaum PL. Gross motor capability and performance of mobility in children with cerebral palsy: a comparison across home, school, and outdoors/community settings. *Phys Ther.* 2004; 84(5):419-29.

11. Ostensjo S, Bjorbaekmo W, Carlberg EB, Vollestad NK. Assessment of everyday functioning in young children with disabilities: an ICF-based analysis of concepts and content of the Pediatric Evaluation of Disability Inventory. *Disabil Rehabil.* 2006; 28(8):489-504.

12. Ketelaar M, Kruijsen AJ, Verschuren O, et al. LEARN 2 MOVE 2-3: a randomized controlled trial on the efficacy of child-focused intervention and context-focused intervention in preschool children with cerebral palsy. *BMC Pediatr.* 2010; 8:10:80.

13. World Health Organization. World Report on Disability. Geneva: WHO; 2011

14. Reinhardt JD, Cieza A, Stamm T, Stucki G. Commentary on Nordenfelt's "On Health, ability and activity: Comments on some basic notions in the ICF". *Disabil Rehabil.* 2006; 28(23):1483-5.

15. Verbeke M. Comments on Nordenfelt. Disabil Rehabil. 2006; 28(23):1481-2

16. Scherer MJ, McAnaney D, Sax C. Opportunity is possibility; performance is action: measuring participation. *Disabil Rehabil*. 2006; 28(23):1467-71.

17. Mcerebral palsy herson K. What are the boundaries of health and functioning-and who should say what they are? *Disabil Rehabil*. 2006; 28(23):1473-4. 18. de Kleijn-de Vrankrijker MW. On health, ability and activity: comments on some basic notions in the ICF. Response on some issues raised by Nordenfelt. *Disabil Rehabil.* 2006; 28(23):1475-6.

19. Nieuwenhuijsen ER. On health, ability and activity: comments on some basic notions in the ICF commentary. *Disabil Rehabil.* 2006; 28(23):1477-9.

20. Morris C. Measuring participation in childhood disability: how does the capability approach improve our understanding? *Dev Med Child Neurol.* 2009;51(2):92-4.

21. World Health Organization. International Classification of Functioning, Disability and Health: ICF. Geneva: WHO; 2001.

22. Trabacca A, Russo L, Losito L, et al. The ICF-CY Perspective on the Neurorehabilitation of Cerebral Palsy: A Single Case Study. J Child Neurol. 2011; [Epub ahead of print].

23. Kembhavi G, Darrah J, Payne K, Plesuk D. Adults with a diagnosis of cerebral palsy: a mapping review of long-term outcomes. *Dev Med Child Neurol.* 2011; 53(7):610-4.

24. Schiariti V, Fayed N, Cieza A, et al. Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning. *Disabil Rehabil.* 2010; 33(15-16):1330-9.

25. Nordenfelt L. Action theory, disability and ICF. *Disabil Rehabil*.2003; 25(18):1075-9.

26. Hemmingsson H, Jonsson H. An occupational perspective on the concept of participation in the International Classification of Functioning, Disability and Health--some critical remarks. *Am J Occup Ther.* 2005; 59(5):569-76.

27. World Health Organization. International Classification of Functioning, Disability, and Health – version for children & youth: ICF-CY. WHO Workgroup for development of version of ICF for Children & Youth. Geneva: World Health Organization; 2007.

28. Rodby-Bousquet E, Hägglund G. Use of manual and powered wheelchair in children with cerebral palsy: a cross-sectional study. *BMC Pediatr.* 2010; 10:59.

29. Andrade PM, Oliveira Ferreira F, Mendonça AP, Haase VG. Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. *Disabil Rehabil.* 2012; [Epub ahead of print]. Doi: 10.3109/09638288.2012.662572

30. Johnston TE, Wainwright SF. Cycling With Functional Electrical Stimulation in an Adult With Spastic Diplegic Cerebral Palsy. *Phys Ther.* 2011; 91(6):970-82.

 Nieuwenhuijsen C, Donkervoort M, Nieuwstraten W, et al. Transition Research Group South West Netherlands. Experienced problems of young adults with cerebral palsy: targets for rehabilitation care. *Arch Phys Med Rehabil.* 2009; 90(11):1891-7.
 Law M, Darrah J, Pollock N, et al. Focus on Function - a randomized controlled trial comparing two rehabilitation interventions for young children with cerebral palsy. *BMC Pediatr.* 2007; 7:31. 33. Schenker R, Coster W, Parush S. Personal assistance, adaptations and participation in students with cerebral palsy mainstreamed in elementary schools. *Disabil Rehabil.* 2006; 28(17):1061-9.

34. Hoare BJ, Imms C, Rawicki HB, Carey L. Modified constraint-induced movement therapy or bimanual occupational therapy following injection of Botulinum toxin-A to improve bimanual performance in young children with hemiplegic cerebral palsy: a randomised controlled trial methods paper. *BMC Neurol.* 2010; 10:58.

35. Retarekar R, Fragala-Pinkham MA, Townsend EL. Effects of aquatic aerobic exercise for a child with cerebral palsy: single-subject design. *Pediatr Phys Ther.* 2009; 21(4):336-44.

36. Boyd R, Sakzewski L, Ziviani J, et al. INCITE: A randomised trial comparing constraint induced movement therapy and bimanual training in children with congenital hemiplegia. *BMC Neurol.* 2010; 10:4.

37. Royal Children's Hospital Melbourne. The Melbourne Assessment of unilateral upper limb function. Available in: http://www.rch.org.au/ot/resources/index.cfm?doc\_id=11095. Acess in 20/05/2011.
38. Mutlu A, Akmese PP, Gunel MK, et al. The importance of motor functional levels from the activity limitation perspective of ICF in children with cerebral palsy. *Int J Rehabil Res.* 2010; [Epub ahead of print]

39. Palisano RJ. A collaborative model of service delivery for children with movement disorders: a framework for evidence-based decision making. *Phys Ther.* 2006; 86(9):1295-305.

40. Andrade PMO, Ferreira, FO, Haase, VG. O uso da CIF através do trabalho interdisciplinar no AVC pediátrico: relato de caso. [The use of the International Classification of Functioning, Disability and Health (ICF-WHO) in interdisciplinary care of stroke in childhood: Case report]. Contextos Clínicos. 2009; 2(1): 27-39 (in Portuguese).

41. Andrade PMO, Ferreira FO, Vasconcelos AG, et al. Cognitive profile, motor deficits and influence of facilitators for rehabilitation for children with neurological dysfunction. *Rev Paul Pedriatr.* 2011; 29(3): 320-27.

42. Meester-Delver A, Beelen A, Hennekam R, et al. The Capacity Profile: a method to classify additional care needs in children with neurodevelopmental disabilities. *Dev Med Child Neurol*. 2007; 49(5):355-60.

43. Siebes RC, Ketelaar M, Gorter JW, et al. Transparency and tuning of rehabilitation care for children with cerebral palsy: a multiple case study in five children with complex needs. *Dev Neurorehabil*. 2007; 10(3):193-204.

44. Morris C, Kurinczuk JJ, Fitzpatrick R. Child or family assessed measures of activity performance and participation for children with cerebral palsy: a structured review. *Child Care Health Dev.* 2005; 31(4):397-407.

45. Badley EM. Enhancing the conceptual clarity of the activity and participation components of the International Classification of Functioning, Disability, and Health. *Soc Sci Med.* 2008; 66(11): 2335-45.

46. Andrade PMO. Avaliação do estágio da fisioterapia conforme as diretrizes curriculares e a perspectiva biopsicossocial da Organização Mundial de Saúde. [Assessment of supervised training of physical therapy as the national curriculum guidelines and the WHO biopsychosocial perspective]. *Avaliação* 2010; 15(2): 121-34. (in Portuguese).

47. de Oliveira-Andrade PM, de Oliveira-Ferreira F, Haase VG. Multidisciplinary perspective for cerebral palsy assessment after an International, Classification of Functioning, Disability and Health training. *Dev Neurorehabil.* 2011; 14(4):199-207.



Figure 1: Article Selection Flow

# 4.5 ESTUDO 5: AN ICF-BASED APPROACH FOR CEREBRAL PALSY FROM A BIOPSYCHOSOCIAL PERSPECTIVE

# Abstract:

The purposes of this study were to integrate instruments to operationalize an ICFbased approach for cerebral palsy (CP); to assess differences in activity and participation among hemiplegic, diplegic and quadriplegic CP children; to verify the facilitators or barriers to functioning; and to investigate the explanatory factors (cognitive and motor) for the type of school attended by CP children (regular or special). 60 CP children were assessed, using the Mini-Mental State Examination and an ICF-based tool and their parents were interviewed. Data were analyzed by Chi-Squared, Anova's and Kruskal-Wallis tests and multivariate logistic regression. Significant differences between CP subgroups were found for chewing, urinary function, cognitive function and activities and participation. Twelve environmental factors were identified as barriers. Multivariate regression identified cognitive function as a significant explanatory variable for the type of school attended, whereas motor function was not significant. The ICF-based approach allows a comprehensive assessment, relevant for planning interventions.

**Keywords:** cerebral palsy, ICF-based approach, cognitive, motor impairment, activities limitations, environmental factors

Short Title: ICF-based approach for cerebral palsy

# 1. Introduction

A biopsychosocial approach based on the International Classification of Functioning, Disability and Health (ICF; WHO, 2011) is a recommendation of the 'World Report on Disability' (WHO, 2011) for the treatment or rehabilitation process of individuals with developmental disabilities. 'Cerebral palsy (CP) describes a group of permanent disorders of the development of movement and posture, causing activity limitation that is attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behavior, epilepsy, and by secondary musculoskeletal problems' (Rosenbaum et al., 2007). The motor impairment may involve different body structures, resulting in specific topographical classifications — tetraplegia/quadriplegia, hemiplegia/hemiparesis and diplegia (Bax et al., 2005). The evaluation and classification of CP is focused on motor impairment, and aspects of cognitive function are not exploited and are neglected in children with CP (Pueyo, Junqué, Vendrell, Narberhaus, & Segarra, 2008; Bottcher, 2010). Cognitive skills may be obscured by impairments in neuromusculoskeletal functioning and limitations in activities related to mobility (Sigurdardottir et al., 2008). The lack of validated assessment tools to evaluate cognitive function in these children may explain the failure to investigate these mental functions. Thus, there is a gap in the literature related to the study of the interactions of the motor and cognitive impairments with the activity limitations. Children with CP need special care related to support for rehabilitation and social interaction. In addition, some studies have linked CP with low socioeconomic status (Sundrum, Logan, Wallace, & Spencer, 2005; Wu et al., 2011) and low birth weight (Spencer, Bambang, Logan, & Gill., 1999). Thus, contextual factors contribute to the etiology and rehabilitation of these children.

The lack of standardized assessments of functioning in health services, the absence of a uniform language among health professionals and the need for transparency in the process of rehabilitation were problems reported by authors from several countries (Siebes et al., 2007; Nijhuis et al., 2008; de Oliveira-Andrade, de Oliveira-Ferreira, & Haase, 2011). Therefore, the use of international classifications is relevant for use in research and clinical practice.

The ICF presents a multidimensional model in which individual components (body functions and structures, activity and participation and contextual factors) can positively or negatively influence the determinants of health (WHO, 2001). This model has feedback loops that allow two-way relationships among its components. The World Health Organization (WHO) advocated for the use of the ICF-based approach, which is aimed at operationalizing the biopsychosocial perspective, for evaluating and intervening in various health conditions (WHO, 2001).

The ICF approach can be operationalized by the use of instruments previously validated for the assessment of specific domains of the classification. It is also important to note that ICF-based tools may extend and simplify the deployment of the multidimensional model of functioning, disability and health. Thus, the ICF-based approach comprises a combination of the existing instruments with tools developed in a biopsychosocial model. The ICF can contribute to the plan of care through the development of children with cerebral palsy (Palisano, 2006).

There is no ICF-based instrument that is specific to CP. The lack of tools related to these constructs may be related to the limited studies regarding this scope. An evaluation that is not based on the ICF model can fragment the measurement procedures and engender observations based on the biomedical model rather than the biopsychosocial perspective. Considering the impact of CP on cognitive and motor functions, the lack of studies related to the assessment of the mental function of children with CP and the need for ICF-based tools for CP assessment, the aims of this study were the following: a) to integrate the instruments for the assessment of motor and cognitive functions, activity and participation and environmental factors to operationalize an ICF-based approach for CP; b) to explore the possibility of an ICFbased tool to discriminate the functioning of hemiplegic, diplegic and quadriplegic CP; c) to verify the presence of the facilitators or barriers to functioning; and d) to investigate the explanatory factors for children's participation in regular or special schools.

#### 2. Methods

The sample for this cross-sectional study was selected from cases registered in a public rehabilitation center and in three special schools.

#### 2.1. Study phases

The study was conducted in two phases: Phase A entailed the definition of the items and instruments for an ICF-based approach, and Phase B was focused on the application of the tools selected in Phase A in an empirical study with cases of CP.

# 2.1.1. Phase A - ICF-based approach for Cerebral Palsy (IBACP)

The ICF-based approach aimed to operationalize the evaluation of the components of the ICF using the tools adapted or developed to reach the objectives of the study. The ICF-based approach for cerebral palsy (IBACP) has ICF categories from five chapters of the body functions ('mental functions', 'sensory functions and pain', 'functions of the digestive system', 'genitourinary functions', and 'neuromusculoskeletal and movement-related functions'); eight activity and participation chapters ('learning and applying knowledge', 'communication', 'mobility', 'self-care', 'domestic life', 'interpersonal interactions and relationships', 'major life

areas', and 'community, social and civic life'); and three environmental factor chapters ('products and technology', 'support and relationships', and 'services, systems and policies') (WHO, 2001).

For the evaluation of the ICF categories, an instrument based on the ICF was developed in this study to assess the components of activity/participation and environmental factors. The Mini-Mental State Examination (MMSE) adapted for children (Jain & Passi, 2005) was used for the investigation of mental function. The 'Brazil Criterion' was used to investigate socioeconomic status (SES) (Brazilian Association of Research Companies, 2011) to identify issues related to the assets (ICF code=e165) and educational level of the household head (ICF code=e310).

#### 2.1.1.1. Instruments available

#### a) Gross Motor Function Classification System (GMFCS)

The severity of the motor disturbance in CP was classified using the Gross Motor Function Classification System (GMFCS) (Palisano, Rosenbaum, Russell, Wood, Galuppi, 1997). The GMFCS grades the self-initiated movement of CP patients with a particular emphasis on their functional abilities (e.g., sitting, crawling, standing, and walking) and their need for assistive devices (e.g., walkers, crutches, and canes) and wheeled mobility. The GMFCS employs a 5-point scale (H-V) ranging from 'independent' or 'less impairment' (level I) to 'dependent' or 'greatest impairment' (level V) (Hiratuka, Matsukura, Pfeifer, 2010).

#### b) Cognitive Assessment – Mini-Mental State Examination

The MMSE is a cognitive screening task adapted and validated by Jain and Passi (2005) for an Indian child population and developed a score system to assess the cognitive function of children from 3 to 14 years old. The MMSE presents 11 questions involving 5 cognitive abilities: attention-concentration, orientation,

registration, recall, language and constructive ability (Jain & Passi, 2005). The research established a score less than two standard deviations below the mean as the cutoff for cognitive impairment. Scores range from 0 to 37 points. The MMSE was selected for this study because it is a simple tool that can be applied both in a short period of time (5-7 minutes) and for a wide age range (3-14 years) and because it is appropriate regardless of the socioeconomic and educational level of the child or adolescent (Jain & Passi, 2005). In addition, a study by Andrade et al. (2011) showed a 94% accuracy rate for discriminating neurological disease in childhood and controls. The MMSE involves 14 subcategories of the third and fourth levels of the ICF mental functions. Table 1 shows the ICF codes and subcategories assessed by the MMSE.

ICF	ICF categories
Codes	
b1140	Orientation to time
b1141	Orientation to place
b1142	Orientation to self
b1440	Short-term memory
b1441	Long-term memory
b1442	Retrieval and processing of memory
b1561	Visual perception
b1565	Visuospatial perception
b1641	Organization and planning
b1643	Cognitive flexibility
b16700	Reception of spoken language
b16701	Reception of written language
b16710	Expression of spoken language
b16711	Expression of written language

Table 1 – ICF categories assessed by the MMSE

# c) Socioeconomic Assessment

The Brazil Economic Classification Criterion (BECC), proposed by the Brazilian Association of Research Companies (ABEP, 2011), was used to assess the socioeconomic status of the participants. In this questionnaire, the educational level of the household head has a value from 0 to 8 points, and the remaining points are provided by the amount of durable consumer goods that the family owns (car, color television, radio, refrigerator, freezer, washing machine clothing, and DVD player), the number of rooms in the house (with an emphasis on bathrooms), and the number of salaried domestic employees who work in the house. The sum of these indicators is used to divide the population into classes. 'Class A1' (42-46 points) is the most favored, and 'Class E' (0-7 points) is the most underprivileged class (ABEP, 2011). Therefore, this instrument assesses the environmental factors related to the products and technology (ICF chapter, e1) owned by the participants' families.

#### 2.1.1.2. Development of ICF-based instrument for cerebral palsy - IBI-CP

Three preliminary studies were developed to support the selection of the categories to comprise the IBI-CP (de Oliveira-Andrade, de Oliveira-Ferreira, & Haase 2011; Andrade et al., 2011; and Andrade, Oliveira-Ferreira, Mendonça & Haase, 2012. An empirical study informed the selection of the categories related to the basic environmental factors (BEFs) and the specific environmental factors (SEFs) (Andrade et al., 2011). A second study aimed to identify the contents of the assessment described in the medical records by professionals from a rehabilitation center (Andrade et al., in press), and the third study involved an expert panel of professionals from different professional backgrounds (de Oliveira-Andrade et al., 2011). The IBI-CP has three domains: a) an ICF body function component, b) an ICF

activities and participation component and c) an ICF environmental factors component.

### a) ICF body function component

The mother or caregiver was interviewed and asked to report impairments or problems in the past month related to vision, hearing, chewing, swallowing, respiratory function and urinary function.

### b) ICF activities and participation component

The interview with the responsible consisted of 28 second and third levels ICF categories from chapters related to activity and participation (e.g., learning and applying knowledge; communication; mobility; self-care; domestic life; interpersonal interactions and relationships; major life areas; and community, social and civic life). This information was classified according to the ICF qualifiers (0 = no difficulty, 1 = mild difficulty, 2 = moderate difficulty, 3 = severe difficulty, 4 = complete difficulty or does not perform the activity) to measure performance. Higher scores indicate greater limitations in activities, while the lowest score is associated with greater functioning or better performance. The maximum score of this instrument is 112 (indicating that the child presents complete difficulty in all 28 items assessed, according to the responsible report), and the minimum score is 0 (indicating that the child presents no difficulty in all 28 items assessed, according to the responsible report).

# c) ICF environmental factors component

The environmental factors component comprises 25 categories, 12 of which are related to basic environmental factors (BEFs) and 13 of which are related to specific environmental factors (SEFs). The variable BEF is constructed with the mean of the scores of the items that are essential for the development and functioning of all participants (i.e., parents, siblings, extended family, friends, play toys, educational services, teachers, and public transport) and does not consider the medical condition. The variable SEF is constructed with the mean of the scores of the items related to specific health care or the rehabilitation process, such as health professionals (i.e., physiotherapist, occupational therapist, speech therapist, and psychologist), special education, use of orthotics and prostheses, and transportation to the rehabilitation center. The qualification of the magnitude of the influence of the environmental factors as barriers or facilitators was performed by parents or caregivers. ICF qualifiers were evaluated on an ordinal scale for the environmental factor). Thus, the total score for the BEF can range from -48 to +48, and the total score for the SEF can range from -52 to +52.

#### 2.1.2. Phase B: Empirical study

The empirical study was conducted in three steps: a) the identification of cerebral palsy cases, b) the recruitment of the participants (mothers and children or adolescents) and c) the assessment and interviews with the children or adolescents and interviews with the mothers or responsible caregivers.

2.1.2.1. Identification of cerebral palsy cases: Cerebral palsy patients between the ages of 6 and 19 years were identified either at the rehabilitation center, which is the rehabilitation referral (a tertiary pediatric neurorehabilitation unit) for the population from the Jequitinhonha Valley in Brazil or from special schools in Diamantina, Guanhães and Pará de Minas, Brazil. Mothers or caregivers were invited to participate in the study.

*2.1.2.2. Sample Size Calculation:* The sample size estimation for group comparison was performed considering a significance level of 95% (Jekel, Katz, & Elmore, 2001).

A pilot study was conducted with fifteen children (five from each group — hemiplegia, diplegia and quadriplegia) to obtain the needed values to conduct the sample size calculation: the standard deviation of the dependent variable. The standard deviation obtained in the pilot study for the activity and participation variable was 20.0 points, and a minimum difference of 15 points in the total score of the activity and participation scale was assumed to be detected between groups. The calculated sample size was 13,6 children per group. To account for non-response, the sample was increased by 10%, resulting in a total of 15 children per group. The formula used was:

# $Z_{\alpha}^{2} x 2 x sd^{2}/d^{2}$

 $Z\alpha$  = The critical level of significance for 95%; *d*= Minimum difference to be detected in the study; *sd*= Standard deviation of the dependent variable in the study.

b) Assessment with the children or adolescents and interviews with the mothers or responsible caregivers: Assessments and interviews were conducted in rooms assigned by the rehabilitation center and the special schools.

#### 2.2. Statistical analysis

The Kolmogorov normality test was used to verify the distribution of the variables. ANOVAs were conducted for group comparisons on continuous variables that presented normal distributions (age, maternal age, number of siblings, BEF and SEF, and MMSE score), and the Kruskal-Wallis test was used for variables that did not present normal distributions (maternal education, socioeconomic status, and activity and participation). Chi squared ( $\chi^2$ ) tests were used to analyze differences in proportions between subgroups.

To verify the associations between the independent variables and the type of school attended by the participants,  $\chi^2$  and Kruskal-Wallis tests were conducted. Multivariate analyses (logistic regressions) were conducted to investigate the associations between the available covariates and the participation of the children in regular or special education. The following were the main criteria for the selection of the independent variables in the regression model: a) inserting variables that had a significant association (p <0.05) with the type of school in the bivariate analyses ( $\chi^2$ , ANOVA and Kruskal-Wallis); b) in terms of the multicollinearity criterion, not inserting two variables that were significantly associated; and c) inserting a maximum of five variables in the multiple model. The statistical significance level used for all tests was 5% (p < 0.05). Analyses were conducted using *SPSS* version 17.0.

#### 3. Results

A total of 60 children and adolescents diagnosed with CP participated in the study. The mean age (SD) was 11.5 (4.1) years; 41.7% of participants attended a regular school, and the sample contained more boys (60%) than girls. Most participants (66.7%) were ambulatory (GMFCS levels I-III) with or without handheld mobility devices. The cases were from 22 cities and lived up to 341 kilometers from the rehabilitation unit (M=107; SD=74.1). The mean number of children per family was 3.4 (SD=1.8; range=1-8 children).

Table 2 summarizes the major characteristics of the study sample and presents the number of CP cases in each subgroup [hemiplegia (n=20), diplegia (n=19) and quadriplegia (n=21)]. Significant differences between the subgroups were found for chewing (p=0.002), urinary function (p< 0.001), cognitive function measured by MMSE (p<0.001) and activities and participation score (p<0.001). The

greatest variability in cognitive function and activity and participation score was found in the diplegia subgroup.

Table 2 - Characteristics of CP cases and results of the instruments for each subgroup	up.
--	-----

Characteristics	Hemiplegia	Diplegia	Quadriplegia	ANOVA	
	Mean (SD)	Mean (SD)	Mean (SD)	F[2]	р
Age (years)	11.0 (4.18)	13.32 (4.28)	10.25 (3.44)	3.11	0.052
Maternal age (years)	38.50 (9.22)	40.53 (6.57)	36.17 (7.83)	1.05	0.359
Number of children in	3.40 (1.46)	3.58 (2.0)	3.35 (2.0)	0.082	0.922
the family					
MMSE score	21.11 (10.75)	20.83 (12.11)	5.85 (9.25)	12.80	0.001*
BEF score	22.44 (9.65)	24.47 (8.40)	21.50 (6.52)	0.61	0.545
SEF score	22.72 (11.0)	27.20 (6.81)	21.65 (8.17)	1.77	0.180
Characteristics	Median (Q1 – Q3)	Median (Q1 – Q3) Me	edian (Q1 – Q3)	Kruskal-	р
				Wallis[2]	
Maternal education	4 (4-11)	4 (3.5-12)	8 (3.50 – 11)	0.488	0.784
Socioeconomic status	11 (9-14)	13.5 (11-19)	13.0 (8.5 – 15)	5.88	0.053
score		/			
Activities and	30 (17-44)	30 (13.75–54.25)	87.50 (71–94.5)	33.38	0.001*
participation (primary					
caregiver interview)					
score	<b>2</b> (	<b>0</b> /	0/	×2	
Impairments in	%	%	%	X <sup>2</sup>	р
Vision function	15.8	31.6	21.1	1.39	0.498
Hearing function	15.8	5.3	0	3.76	0.152
Chewing function	5	10.5	36.8	7.81	0.002*
Swallowing function	15	26.3	26.3	0.96	0.617
Respiratory function	31.6	15.8	21.1	1.39	0.498
Urinary functions	10	31.6	78.9	20.12	0.000*

BEF = Basic Environmental Factors – SEF= Specific Environmental Factors - Kruskal-Wallis[2] and  $\chi^2$  tests were selected for nonparametric data analysis, and an ANOVA was selected for continuous data analysis - \* p < 0.05

Table 3 shows the socioeconomics status of the CP cases. Comparing the socioeconomic distribution of the Brazilian population with the socioeconomic distribution of the participants of the present study, we found that 57% of the cases were in Classes D and E (mean monthly family income of \$380), while 18% of the Brazilian population is classified in Classes D and E.

Social class	Average family income* (U\$\$)	Hemiplegia	Diplegia	Quadriplegia	General	Brazil *
A1	6.413	0%	0%	0%	0%	0.5%
A2	4.634	0%	5.6%	0%	1.8%	4.0%
B1	2.656	0%	5.6%	5%	3.5%	9.1%
B2	1.484	0%	0%	0%	0%	19.3%
C1	815	5.3%	27.8%	5%	12.3%	25.6%
C2	537	26.3%	16.7%	35%	26.3%	23.2%
D	380	52.6%	44.4%	50%	49.1%	17.1%
Е	232	15.8%	0%	5%	7%	1.1%
Total		100%	100%	100%	100%	100%

Table 3 – Socioeconomic status according to the motor impairment

\*Reference: Brazilian Association of Research Companies (2009) – Conversion to the Dollar (U\$ 1,00 = R\$ 1.79).  $X^2$  = 13.12, p = 0.217

No significant differences in socioeconomic status were found either between groups (p = 0.217) or between children who attended regular or special schools (p=0.910). Table 4 shows the difficulties associated with each activity (learning, communication, mobility, self care, domestic life, and schooling and community life) as assessed by the maternal interview. Significant differences were found between the three groups for 23 categories. No differences were found for activities related to interpersonal relationships (child-parent relationships and siblings relationships), school education and socializing. The largest differences ( $\chi^2 > 40$ ) were found between groups for standing, maintaining a standing position and eating activities. A lack of associations between impairments and limitations in functionality were verified because there were functional limitations in cases who had mild disabilities (e.g., 57.9% of the hemiplegic children presented complete difficulty with learning activities, such as calculating); in contrast, no limitations in other abilities were found in more severe cases of impairment (e.g., 30% of the quadriplegic children presented no difficulty with receiving and understanding spoken messages).

# (INSERT TABLE 4, PAGE 150)

Table 5 presents the barriers for functioning as related by parents. Twelve ICF environmental factor categories were described as barriers. Paternal absence, recorded by the qualifier as 0, is shown in Table 5.

Case	Motor	GMFCS	Age	Sex	SES	Barriers	ICF	
	Impairment						Qualifier	
							(total)	
1	Hemiplegia	I	14	F	E	Assistive products and	-4	
						technology for personal use		
				_	_	in daily living (Tutor)		
2	Hemiplegia	I	8	F	D	Father = B	-14	
						Siblings		
						leachers		
						Television		
						Prejudices of other children		
			-	_		at school		
3	Hemiplegia	I	8	F	C2	Father = B	-6	
			•	_	00	Regular School		
4	Hemiplegia		6	F	C2	Father = B	-4	
5	Hemiplegia		14		D	l utor	-1	
6	Diplegia	1	11	F	B1 00	Speech Therapy	-4	
1	Dipiegia	П	10	F	62	Drugs Desular Sahaal	-2	
0	Diplogia		10	N.4	Р	Regular School	F	
0	Dipiegia	111	12	IVI	D	Falliel = D	-5	
0	Diplogia		10	F	П	Fethor – 0	0	
9 10	Diplegia		19	Г М		Father = $0$	0	
10	Diplogia		17	N/		Father $= 0$	0	
12	Ouadrinlagia		1/	F		Assistive products and	-1	
12	Quaunpiegra		14	1	D	technology for personal use	- 1	
						in daily living (Walker)		
13	Quadrinlegia	V	6	F	C2	Father – B	-8	
10	Quadriprogra	v	U		02	Public transportation	0	
14	Quadriplegia	V	8	F	D	Father = $0$	0	
15	Quadriplegia	v	14	M	D	Father = $0$	Ő	
16	Quadriplegia	v	4	M	D	Father = $0$	-10	
	a da an progra	•	•		_	Extended family		
						Friends		
						Teachers		
						Public transportation		
B=Bar	B=Barrier (ICF qualifier codes -1-4) - SES=Socioeconomics Status – M=male – F=Female							

# Table 5 - Barriers for functioning related by parents

Logistic regression analyses were conducted to investigate the influence of functions and activities on the attendance of children in regular schools or special schools. The independent variables were age, the total score on the MMSE, the GMFCS classification, urinary function, standing and eating. The dependent variable was the enrollment of children in regular or special schools. Regular school was used as the reference in the regression model. Univariate analysis was initially conducted to assess the influence of each independent variable on the outcome. Univariate analysis showed that higher MMSE scores were a predictor for participation in regular schools, indicating that higher scores on the MMSE decreased the likelihood of children attending special schools. In the univariate model, the GMFCS classification (IV and V), impairment in urinary function and limitation in standing and eating were also significant explanatory factors for attendance in special schools. The Odds Ratio indicates that children that presented impairment in urinary function were seven times more likely to attend special schools. However, when all the independent variables were included in the regression model, only the MMSE scores remained significant. This result indicates that when urinary function, cognitive function and motor functioning are considered together, the major explanatory factor to attendance in special or regular schools is cognitive function, suggesting that the increase in the MMSE score decreased the likelihood of attending special school independently of motor and urinary function. The results of the regression analysis are presented in Table 6.

	Univariate					
	Regression			Multivariate Regression		
	OR (95%CI)	df	р	OR adj (95%Cl)	df	р
Age	1.023 (0.894-1.170)	1	0.740			
MMSE score	0.876 (0.818-0.937)	1	< 0.001	0.876 (0.805-0.954)	1	0.002*
GMFCS (IV, V)	4.632 (1.295-16.576)	1	0.018	0.988 (0.112-86.701)	1	0.991
Impairment in						
urinary function	7.269 (2.01-26.28)	1	0.002	2.039 (0.330-12.604)	1	0.443
Eating limitation						
(2,3,4)	4.250 (1.302-13.874)	1	0.017	0.514 (0.060-4.420)	1	0.545

Table 6: Univariate and multivariate OR from a logistic regression model for predicting participation in special schools

OR=odds ratio - 2,3,4=ICF qualifiers (moderate, severe and complete difficulty) - df=degrees of freedom - \* p<0.05

#### 4. Discussion

Information on rehabilitation services is mostly incomplete and fragmented [WHO, 2011; Andrade et al., (in press)]. The ICF-based approach proposed in the present study through the use of pre-existing instruments and the development of an ICF-based instrument for CP can help systematize the use of the biopsychosocial approach endorsed by WHO in rehabilitation services (WHO, 2011). This approach enables an understanding of the impairments (motor and cognitive), activity limitations and contextual factors that underlie development and are specific to the rehabilitation process. Thus, this study introduced an ICF-based tool for defining a functional profile for CP. The results provide relevant information for stakeholders, such as health professionals (who do not perform a structured evaluation in rehabilitation services), schools, parents, and policy makers for use in advocating for future improvements in services for children with CP.

The socioeconomic status of participants in the present sample was lower than that of the general Brazilian population. Studies have shown that there are etiological factors of CP that are mediated by a low socioeconomic condition (Sundrun et al., 2005; Spencer et al., 1999; Wu et al., 2011). A large family size can be an aggravating factor of poor socioeconomic conditions. There were a large number of children per family in our sample, with a maximum of nine children. The average number of children observed in the present sample was 3.4 children per family. Another factor that may be considered a barrier to rehabilitation is the absence of fathers in families in 29% of cases. Low family income may explain household demand for public or philanthropic rehabilitation despite the distance of the service from their city of origin.

Barriers related to public transportation, equipment for mobility, health professionals, drugs and families were reported (de Oliveira-Andrade et al., 2011). Knowledge of barriers related to families and the rehabilitation process can help to enhance rehabilitation activities and public health policies (WHO, 2011). The proposal to insert new categories and to discriminate into subcategories items not covered by ICF, such as father and mother, health professionals (e.g., physiotherapy, occupational therapy, speech therapy) and type of health service, enabled a more specific evaluation of environmental factors (de Oliveira-Andrade et al., 2011). These subcategories may be introduced in the ICF update.

The evaluation of the cognitive aspects of CP cases enhances the understanding of their special education needs and the potential of children to improve their learning, communication, interpersonal relationships and community life. A cognitive rehabilitation program could be developed from the knowledge of cognitive impairments and learning and communication difficulties. The absence of a neuropsychological assessment in the Brazilian public rehabilitation service system and special schools may limit the evaluation and rehabilitation of the mental functions of CP cases. The assessment of cognitive abilities could guide educators in the optimization of cognitive development and learning. Teaching practices could be directed toward compensating for difficulties and stimulating the potential abilities of children and adolescents. This practice may contribute to the following WHO recommendation: '...all students should have access to a curriculum that is relevant and produces meaningful outcomes' (WHO, 2011, p. 209). Parents reported unpreparedness and neglect on the part of schools and/or teachers in ascertaining the learning difficulties of CP children. There is a need for improved communication between the professionals involved in rehabilitation and education to implement integrated actions.

No significant differences in parental perceptions of the children were found between the three groups (hemiplegia, diplegia and quadriplegia) regarding childparent relationships, sibling relationships, socializing and school education. This finding indicates that the parents of children with more severe motor impairments did not perceive a greater impact on these activities than did the parents of children with mild impairment, which suggests that parental perceptions of the difficulties for these activities is the same across different levels of motor impairment. This result indicates that there is not a linear relationship between impairments and limitations for these activities from the perspectives of the parents.

Only qualifier performance was used to assess activity and participation. Studies are needed to investigate the relationship between the capacity of children

142

and their daily performance. It is possible that some children do not perform some activities due to overprotection or lack of encouragement from their families. Several parents reported that children did not perform some activities (ICF qualifier=4, Table IV). For example, children with hemiplegia could perform activities such as caring for teeth, cleaning cooking utensils, and washing themselves, but the parents reported that the could not perform these activities. Educational activities with the parents could encourage autonomy for these children and adolescents. In addition, future studies with this instrument should evaluate stability over time, responsiveness in intervention studies and test-retest reliability.

Parental perceptions regarding the participation of children in educational activities were similar in the three subgroups, and no significant differences were found between groups in this aspect. Considering motor impairment and cognitive functioning together in the regression model, cognitive functioning had a more significant influence on attendance in special or regular schools. Therefore, cognitive functioning can be considered a more powerful explanatory factor than motor impairment for attendance in special or regular schools. This evidence reinforces the need for a cognitive classification level system for CP cases. This cognitive classification system could facilitate the educational process of children in regular or special schools.

There are limitations to this study. First, this study was based on a nonprobabilistic sample and was therefore not a population-based study. A populationbased study would better illustrate the actual conditions and functioning of children who require a service and do not require rehabilitation and/or special education. Nevertheless, this methodological design limitation with large within-group variability is inherent to rehabilitation or clinical studies (Ottenbacher, 1990; Kroll & Morris, 2009) conducted with a special needs sample because rehabilitation centers are a better location to recruit patients with developmental delays or acquired impairments. However, this study performed a sample size calculation to reach statistical power. Sample size calculations were not used in other studies that proposed to develop ICF-based tools, although these calculations are recommended to prevent both type I error (false positives) and type II error (false negatives) (Abdul, Daud Amadera, Pimentel, Pimentel, & Fregni, 2011).

An ICF-based approach should be employed by a team of rehabilitation professionals such as physicians, physiotherapists, psychologists, speech therapists, occupational therapists and social workers, as each area can identify problems, potential functional capacities and environmental barriers. The integration of these interdisciplinary approaches can effectively operationalize a biopsychosocial perspective. This structured approach could avoid gaps in evaluation. A full assessment according to the biopsychosocial perspective should involve an assessment in the family home. This type of evaluation allows professionals to understand the real barriers and facilitators that help or hinder functioning. Future studies must develop an assessment of the context of the family for an on-site observation.

The lack of instruments that are based on the biopsychosocial perspective represents a challenge for research related to the study of functioning. The present approach illustrates the feasibility of developing a clinical measure based on the ICF framework of functioning and disability, which represent body functions, activities and participation and environmental factor domains. The results suggest that in the future, health care providers will be able to use ICF categories to create a functioning
profile as a starting point both in planning interventions and in providing clinical or educational management.

## References

- Abdul Latif, L., Daud Amadera, J.E., Pimentel, D., Pimentel, T., & Fregni, F. (2011). Sample size calculation in physical medicine and rehabilitation: a systematic review of reporting, characteristics, and results in randomized controlled trials. *Archives of Physical Medicine and Rehabilitation*, 92(2), 306-315. doi: 10.1016/j.apmr.2010.003.
- Andrade, P.M.O., Ferreira, F.O., Mendonça, A.P., & Haase, V.G. (in press). Content identification of the interdisciplinary assessment of cerebral palsy using the International Classification of Functioning, Disability and Health as reference. *Disability and Rehabilitation.*
- Andrade, P.M.O., Ferreira, F.O., Vasconcelos, A.G., Lima, E.P., & Haase, V.G. (2011). Cognitive profile, motor deficits and influence of facilitators for rehabilitation for children with neurological dysfunction. *Revista Paulista de Pediatria*, 29(3), 320-327. doi: 10.1590/S0103-05822011000300003.
- Bax, M., Goldstein, M., Rosenbaum, P., Leviton, A., Paneth, N., Dan, B., Jacobsson,
  B., & Damiano, D. (2005). Proposed definition and classification of cerebral palsy,
  April 2005. *Developmental Medicine and Child Neurology*, 47(8), 571-576. doi:
  10.1111/j.1469-8749.2005.tb01195.x.

- Bottcher, L. (2010). Children with spastic cerebral palsy, their cognitive functioning, and social participation: a review. *Child Neuropsychology*, 16 (3), 209-228. doi: 10.1080/09297040903559630.
- Brazilian Association of Research Companies. (2011). *Critério de classificação econômica Brasil.* Access in <http://www.abep.org/codigosguias/ABEP\_CCEB.pdf>, march 10, 2011.
- Hiratuka, E., Matsukura, T.S., & Pfeifer L.I. (2010). Adaptação transcultural para o Brasil do Sistema de Classificação da Função Motora Grossa (GMFCS). [versão eletrônica], *Revista Brasiliera de Fisioterapia*, 14(6), 537-544. doi: 10.1590/S1413-35552010000600013.
- Jain, M., & Passi, G.R. (2005). Assessment of a modified mini-mental scale for cognitive functions in children. *Indian Pediatrics*, 42(9), 907-912. Access in http://www.indianpediatrics.net/sep2005/907.pdf.
- Jekel, J.F., Katz, D.L., & Elmore, J.G. (2001). *Epidemiology, biostatistics, and preventive medicine* (2nd ed.). Elsevier. Atlanta, USA.
- Kroll, T., & Morris, J. (2009). Challenges and opportunities in using mixed method designs in rehabilitation research. Archives of Physical Medicine and Rehabilitation, 90(11 Suppl), 11-16. doi: 10.1016/j.apmr.2009.04.023

- Nijhuis, B.J., Reinders-Messelink, H.A, .de Blécourt, A.C, Boonstra, A.M., Calamé, E.H., Groothoff, J.W., Nakken, H., Postema, K. (2008). Goal setting in Dutch paediatric rehabilitation. Are the needs and principal problems of children with cerebral palsy integrated into their rehabilitation goals? *Clinical Rehabilitation*, 22(4), 348-363. doi: 10.1177/0269215507083055.
- de Oliveira-Andrade, P.M., de Oliveira-Ferreira, F., & Haase, V.G. (2011).
   Multidisciplinary perspective for cerebral palsy assessment after an International,
   Classification of Functioning. *Disability and Health training, Developmental Neurorehabilitation*,14(4), 199-207. doi: 10.3109/17518423.2011.584781.
- Ottenbacher, K.J. (1990). Clinically relevant designs for rehabilitation research: the idiographic model. *American Journal of Physical Medicine and Rehabilitation*, 69(6), 286-292.
- Palisano, R.J., Rosenbaum, P., Russell, D., Wood, E., & Galuppi, B. (1997).
  Development and reliability of a system to classify gross motor function in children of cerebral palsy. *Developmental Medicine and Child Neurology*, 39(4), 214-223.
  doi: 10.1111/j.1469-8749.1997.tb07414.x.
- Palisano R.J. (2006). A collaborative model of service delivery for children with movement disorders: a framework for evidence-based decision making. *Physical Therapy*,86(9):1295-1305. doi: 10.2522/ptj.20050348.
- Pueyo, R., Junqué, C., Vendrell, P., Narberhaus, A., & Segarra, D. (2008). Raven's Coloured Progressive Matrices as a measure of cognitive functioning in Cerebral

Palsy. [Eletronic version], Research Journal of Intellectual Disabilities Research, 52(Pt5), 437-445. doi: 10.1111/j.1365-2788.2008.01045.x.

- Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., Dan,
  B., & Jacobsson, B. (2007). A report: the definition and classification of cerebral palsy. *Developmental Medicine and Child Neurology*, 49, 8-14. doi: 10.1111/j.1469-8749.2007.00201.x.
- Siebes, R.C, Ketelaar, M., Gorter, J.W., Wijnroks, L., De Blécourt, A.C., Reinders-Messelink ,H.A., Van Schie, P.E., & Vermeer, A. (2007). Transparency and tuning of rehabilitation care for children with cerebral palsy: a multiple case study in five children with complex needs. *Developmental Neurorehabilitation*, 10(3), 193-204. doi: 10.1080/13638490601104405.
- Sigurdardottir, S., Eiriksdottir, A., Gunnarsdottir, E., Meintema, M., Arnadottir, U., & Vik, T. (2008). Cognitive profile in young Icelandic children with cerebral palsy. Developmental Medicine and Child Neurology , 50(5), 357-362. doi: 10.1111/j.1469-8749.2008.02046.x.
- Spencer, N., Bambang, S., Logan, S., & Gill, L. (1999). Socioeconomic status and birth weight: comparison of an area-based measure with the Registrar General's social class. *Journal of Epidemiology & Community Health*, 53(8), 495-498. doi: 10.1136/jech.53.8.495.

- Sundrum, R., Logan, S., Wallace, A., & Spencer, N. (2005). Cerebral palsy and socioeconomic status: a retrospective cohort study. *Archives of Disease in Childhood*, 90(1),15-18. doi: 10.1136/adc.2002.018937.
- World Health Organization. (2001). ICF Checklist Version 2.1a, Clinical Form for International Classification of Functioning, Disability and Health: ICF. Geneva: WHO.

World Health Organization. (2011). World Report on Disability. Geneva: WHO.

Wu, Y.W., Xing, G., Fuentes-Afflick, E., Danielson, B., Smith, L.H., & Gilbert, W.M.
(2011). Racial, ethnic, and socioeconomic disparities in the prevalence of cerebral palsy, *Pediatrics*, 127(3), 674-681. doi: 10.1542/peds.2010-1656.

	Hemiplegia				Diplegia				Quadriplegia			Statistics					
ICF	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	X <sup>2</sup>	р
CODES	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%	df=8	
d166	10.5	10.5	10.5	26.3	42.1	31.3	6.3	6.3	6.3	50	0	0	5	5	90	17.72	0.023*
d170	47.4	10.5	15.8	5.3	21.1	50	12.5	6.3	6.3	25	0	0	0	5	95	28,98	<0.001*
d172	15.8	10.5	10.5	5.3	57.9	37.5	6.3	0	12.5	43.8	0	0	0	5	95	18.13	0.020*
d310	73.7	10.5	5.3	10.5	0	81.3	6.3	6.3	6.3	0	30	15	30	5	20	18.03	0.021*
d330	42.1	15.8	10.5	26.3	5.3	43.8	6.3	25	18.8	6.3	10	5	5	15	65	25.85	<0.001*
d3352	36.8	21.1	0	21.1	21.1	37.5	18.8	6.3	25	12.5	5	5	0	20	70	19.66	0.012*
d4103	89.5	10.5	0	0	0	68.8	6.3	18.8	6.3	0	20	0	20	10	50	33.53	<0.001*
d4153	100	0	0	0	0	81.3	18.8	0	0	0	35	5	15	10	35	31.56	<0.001*
d4104	94.4	0	5.6	0	0	43.8	12.5	31.3	0	12.5	0	0	10	10	80	52.58	<0.001*
d4154	73.7	5.3	0	21.1	0	50	18.8	12.5	12.5	6.3	5	0	5	10	80	43.80	<0.001*
d4351	63.2	15.8	5.3	15.8	0	43.8	0	18.8	12.5	25	15	0	0	0	85	38.29	<0.001*
d445	42.1	15.8	31.6	10.5	0	50	6.3	31.3	6.3	6.3	15	15	5	10	55	24.67	0.002*
d450	63.2	15.8	15.8	5.3	0	62.5	6.3	6.3	12.5	12.5	5	5	5	5	80	35.80	<0.001*
d510	63.2	0	15.8	5.3	15.8	50	6.3	6.3	0	37.5	0	0	0	5	95	31.28	<0.001*
d5201	55.6	22.2	11.1	5.6	5.6	61.5	7.7	7.7	0	23.1	5	5	5	5	80	27.58	0.001*
d5400	50	11.1	27.8	5.6	5.6	69.2	0	7.7	15.4	7.7	5	0	0	15	80	39.61	<0.001*
d5402	31.6	15.8	21.1	5.3	26.3	37.5	18.8	6.3	6.3	31.3	0	0	0	10	90	25.25	0.001*
d550	84.2	10.5	5.3	0	0	75	0	0	18.8	6.3	5	0	20	15	60	42.89	<0.001*
d560	89.5	5.3	5.3	0	0	68.8	6.3	12.5	12.5	0	10	15	10	5	60	37.36	<0.001*
d6401	31.6	5.3	10.5	10.5	42.1	37.5	12.5	12.5	6.3	31.3	0	0	5	0	95	19.66	0.012*
d6402	26.3	0	31.6	0	42.1	37.5	0	18.8	18.8	25	0	0	5	0	95	26.70	<0.001*
d7601**	57.9	0	0	5.3	36.8	68.8	0	6.3	6.3	18.8	60	5	0	10	25	5.80	0.669
d7601***	94.7	0	0	0	5.3	81.3	0	6.3	0	12.5	90	0	0	0	10	3.14	0.534
d7602	64.7	17.6	0	0	17.6	73.3	6.7	6.7	6.7	6.7	80	5	0	5	10	6.41	0.601
d820	38.9	16.7	5.6	16.7	22.2	43.8	18.8	6.3	12.5	18.8	20	15	15	5	45	6.73	0.566
d9200	33.3	27.8	33.3	5.6	0	56.3	25	12.5	6.3	0	10	0	15	15	60	35.19	<0.001*
d9201	57.9	0	5.3	5.3	31.6	31.3	0	18.8	6.3	43.8	0	0	5	0	59.4	22.28	0.001*
d9205	84.2	10.5	0	5.3	0	75	0	12.5	6.3	6.3	31.6	0	21.1	15.8	31.6	21.67	0.006

\* p < 0.05 \*\*Father-child Relationship \*\*\* Mother-child Relationship - 0= no activity problem, 1= mild problem, 2= moderate problem, 3= severe problem,

4=complete problem or does not perform the activity

## 5 CONCLUSÕES

Ao se considerar a abrangência da CIF, existem vários desafios teóricos e metodológicos para uma efetiva implantação da perspectiva biopsicossocial da OMS. A falta de consensos sobre o conteúdo da avaliação funcional, a carência de instrumentos, o desconhecimento da CIF, a formação dos profissionais relacionada com o modelo biomédico de atenção à saúde, a complexidade e os poucos estudos no Brasil e em países em desenvolvimento sobre a CIF são alguns dos fatores que dificultam a efetiva aplicação do modelo multidimensional de funcionalidade, incapacidade e saúde na prática clínica dos serviços de saúde e em pesquisas.

A literatura relacionada com o estudo da PC aborda com maior freqüência o estudo das habilidades motoras. A classificação das funções motoras e atividades relacionadas com a mobilidade de casos de paralisia cerebral são realizadas através do GMFCS. Porém, o número de estudos que investigam os aspectos cognitivos e fatores ambientais é relativamente menor, em comparação com a freqüência de pesquisas sobre os aspectos motores da PC. O Mini-Exame do Estado Mental já é um instrumento consolidado para a investigação das habilidades cognitivas da população adulta, porém o uso em crianças é raro e incipiente. As conclusões do Estudo 1 de acurácia e sensibilidade do instrumento para identificação ou rastreamento de problemas nas funções cognitivas representa uma evidência de utilidade deste instrumento para a população infantil com deficiências neurológicas. Além disso, a avaliação cognitiva é relevante, pois pode existir uma dissociação entre as funções cognitivas e motoras em casos de disfunções neurológicas na infância. A integração da avaliação motora, cognitiva e contextual pode ampliar a perspectiva reducionista empregada na prática clínica. O estudo de prontuários de um serviço de reabilitação e o levantamento de itens para avaliação da PC foram estudos preliminares relevantes para a concepção do conteúdo de um instrumento baseado na CIF para investigação da funcionalidade de casos de PC. Os profissionais de saúde do serviço de reabilitação realizam o registro nos prontuários de uma maneira não sistematizada, sendo que as informações descritas apresentam um padrão heterogêneo considerando-se o conteúdo e número de categorias relacionadas com o processo de funcionalidade, incapacidade e saúde. É necessário o desenvolvimento de um consenso sobre questões de avaliação e registro em prontuário para casos de PC . Este consenso poderia ser baseado no modelo e terminologia da CIF.

Por outro lado, são necessários treinamentos sobre a CIF para os profissionais envolvidos com a reabilitação, pois estes profissionais desconhecem aspectos básicos da CIF relacionados com os objetivos, conceitos, terminologia, organização e composição da classificação. Poucos profissionais inseridos na prática clínica apresentam interesse por novos conhecimentos para o aprimoramento dos procedimentos de avaliação e registro em prontuários. Conhecimentos sobre a CIF serão necessários, pois a Política Nacional de Pessoas com Deficiências (Ministério da Saúde, 2009) e algumas resoluções das áreas profissionais (Resolução do COFFITO nº 367, de 2009) já exigem a adoção da classificação da OMS pelos profissionais de saúde.

152

A avaliação e classificação dos fatores ambientais em básicos e específicos pelos estudos 1 e 5 demonstram a necessidade de mais estudos sobre o papel dos fatores ambientais de acordo com necessidades gerais e aspectos relevantes especificamente para o processo de recuperação ou reabilitação da funcionalidade na infância. A classificação dos fatores ambientais é uma inovação que pode ser adotada para a elaboração de instrumentos relacionados com o estudo dos aspectos contextuais relacionados com a investigação da funcionalidade humana. O conhecimento dos fatores contextuais relacionados com a funcionalidade de pessoas com deficiências pode contribuir para a elaboração, monitoramento e avaliação das políticas públicas relacionadas com os determinantes е condicionantes da saúde, tais como, políticas de transporte, moradia, renda, alimentação, educação, lazer e acesso aos bens e serviços essenciais definidos na Lei Orgânica da Saúde (Lei Federal 8.080/90).

Alguns conceitos como de capacidade e desempenho para o estudo da atividade e participação são negligenciados ou utilizados pelos pesquisadores sem considerar as definições da CIF. Este fato pode ocorrer devido às diferentes possibilidades metodológicas para o estudo de limitações de atividade e restrição de participação. A indefinição com relação ao uso de suporte ou facilitadores durante a avaliação da capacidade representa uma dificuldade para operacionalização deste construto de forma consensual. Um amplo debate sobre o estudo da capacidade e desempenho é necessário para a definição de procedimentos metodológicos padronizados para a avaliação do componente da CIF de atividade e participação. Novas perspectivas conceituais foram levantadas com o objetivo de iniciar este debate. A avaliação do desempenho potencial das crianças pode contribuir para a elaboração dos objetivos

da reabilitação centrados não somente nos componentes de estrutura e função do corpo (proposta biomédica tradicional) e nas limitações de atividade e restrição de participação. O enfoque no desempenho potencial pode aumentar a adesão das famílias no processo de reabilitação e facilitar a medida do impacto dos serviços de reabilitação nas habilidades não exploradas pela criança ou adolescente.

O instrumento baseado na CIF para avaliação da PC mostrou-se sensível para mostrar diferenças significativas entre os grupos de hemiplegia, diplegia e quadriplegia para duas funções do corpo (funções urinárias e deglutição) e 20 categorias de atividade e participação. Por outro lado, foram observadas semelhanças para categorias relacionadas com os fatores ambientais e relações e interações interpessoais. Novos estudos com este instrumento são necessários para a investigação de suas propriedades psicométricas.

O estudo 5 apresenta evidências relacionadas com a importância das funções cognitivas para a definição da participação dos casos de PC em escolas regulares ou especiais. Estes achados sugerem a necessidade da incorporação da avaliação cognitiva, com instrumentos validados, pelos serviços de reabilitação e para a tomada de decisão sobre a matrícula na escola regular ou especial.

O estudo de aspectos multidimensionais da funcionalidade humana representa um desafio, pois a investigação de relações lineares de causa e efeito são mais conhecidas e utilizadas pelos pesquisadores. Por outro lado, as barreiras teóricas e metodológicas relacionadas com o estudo de questões multivariadas da funcionalidade, incapacidade e saúde não podem ser motivo da negligência ou

omissão por parte dos pesquisadores, profissionais de saúde, educadores e gestores. Ações integradas entre os setores e o trabalho interdisciplinar são indispensáveis para uma efetiva implantação da perspectiva biopsicossocial da OMS.

Novos estudos são necessários para apresentar novas perspectivas teóricas e metodológicas relacionadas com o modelo multidimensional da CIF. O desenvolvimento de um prontuário eletrônico, baseado em uma checklist da CIF, para a documentação das informações, a elaboração de relatórios para as crianças com disfunções neurológicas, o estudo das característias psicométricas dos instrumentos desenvolvidos, um programa de capacitação permanente dos profissionais de saúde e o apoio financeiro para pesquisas relacionadas com a CIF serão esforços necessários para uma efetiva consolidação do enfoque biopsicossocial na atenção à saúde.

CODE	PHY	РТ	ST	ОТ	PSY	SW	DT
s		Х		Х			X
s320			Х				
s710			Х				
s7104		Х	X				
s7201		X					
s730		X		X			
\$73001			-				
\$73021							
\$73021	x	X		x			
s750		X		X			
s75011	Х	Х		Х			
s75021	Х	Х					
s760	Х	Х					
s7600	Х	Х					
s3203			X				
s Total	05	13	04	05	00	00	01
b	PHY	РТ	ST	ОТ	PSY	SW	DT
- b1			~ - X	X X	-~-	~	
b1 14			Λ	X	x		
b134					X	X	
b140			Х	Х	X		
b152		Х			X		
b160					Х		
b167		Х	X	Х			
b172					X		
b1260			X		X	*7	
b1263		X		v	X	X	
b210 b230							
b230				Λ	x		
b2351		X		Х			
b2402	Х	Х		Х			
b440			X				
b5							Х
b5102			X				Х
b5104			X				
b5105			X				X
b5106		v	X	v			
b5255		Λ		Λ			v
b530 b6202		x		x			Λ
b710	Х	X		X			
b730	Х	Х	Х	Х			
b735		Х	Х	Х			
b7501		X					
b760	X	X		X			
b7600		Х		X			
b7002	v	v					
h Total	A 05	л 17	11	л 17	00	02	04
d	PHV	17 PT	ST	0T	PSV	SW	DT
dl	1111		51	01	X	511	
d130				X			
d166				Х			
d170				X			
d310			X		X		
d315			X				
d330	X	X	X	X	X	X	
d535 d2250			Х	Х	v		
d4103				v	Λ		
d4104		x					
d4153	x	X	X	X			
d4201		X					
d440				Х			
d4455		Х					

d450	X	Х	Х	Х		Х	
d510		Х		Х			
d520				Х			
d540		Х		Х			
d5402				Х			
d550		Х		Х		Х	Х
d760					Х		
d820					Х		
d920					Х		
d Total	03	09	06	15	07	03	01
e	PHY	РТ	ST	ОТ	PS Y	SW	DT
e1100			Х				Х
e1101	Х	Х				Х	
e1151	Х	Х	Х				
e250				Х			
e2500			Х				
e310					Х		
e320			Х				
e355						Х	
e5850					Х		
e5853						X	
e Total	02	02	04	01	02	03	01
15	41	25	38	18	08	07	

Estudo 2 - Table 2- Items of interest in each work area during the evaluation of cases of cerebral palsy according to the ICF components of body structures, body functions, activity and participation and environmental factors. PHY = Physician, PT = Physical Therapist, ST = Speech Therapist, OT = Occupational Therapist, PSY = Psychologists, SW= Social Workers, DT= Dieticians

S	PHY	PT	ST	ОТ	PSY	SW	DT	Total
s3			Х					01
s7	Х	Х	Х	Х				04
S	01	01	02	01	00	00	00	
b	PHY	РТ	ST	ОТ	PSY	SW	NT	
b1		X	Х	Х	Х	Х		05
b2		X		X	X			03
b4			Х					01
b5		Х	Х	Х			Х	04
b6		Х		X				02
b7	X	Х	X	X				04
b	01	05	04	05	02	01	01	
d	PHY	PT	ST	ОТ	PSY	SW	DT	
d1				X	X			02
d3	X	X	X	X		X		05
d4	Х	Х	Х	Х				04
d5		X		X		X	Х	04
d7					X			01
d8					X			01
d9					X			01
d	02	03	02	04	04	02	01	
e	PHY	РТ	ST	ОТ	PSY	SW	DT	
e1	X	X	X			X	X	05
e2			X	X				02
e3			X		X	X		03
e5					X	X		02
e	01	01	03	01	02	02	01	
Total	05	10	11	11	08	06	03	
number of								
chapter =								
19								

**Estudo 2- Table 3 -** ICF chapters covered by at least one subcategory of the second level of the ICF for each professional field. PHY = Physician, PT = Physical Therapist, ST = Speech Therapist, OT = Occupational Therapist, PSY = Psychologists, SW= Social Workers, DT = Dieticians.