

Functional profiles & transition areas for adolescents & adults with cerebral palsy

Mary Jo Cooley Hidecker, PhD, CCC-A/SLP

Assistant Professor, Communication Disorders, U of Wyoming

Adjunct Asst Prof, Epidemiology & Biostatistics, MSU

MaryJo.CooleyHidecker@uwyo.edu

This research is being conducted with:

Edward A. Hurvitz, MD

University of Michigan

Jan Willem Gorter, MD, PhD

Laura Wong

CanChild Centre for Childhood
Disability Research,
McMaster University

Toni Benton, MD

John Phillips, MD

University of New Mexico

Beth Young Jones, MS

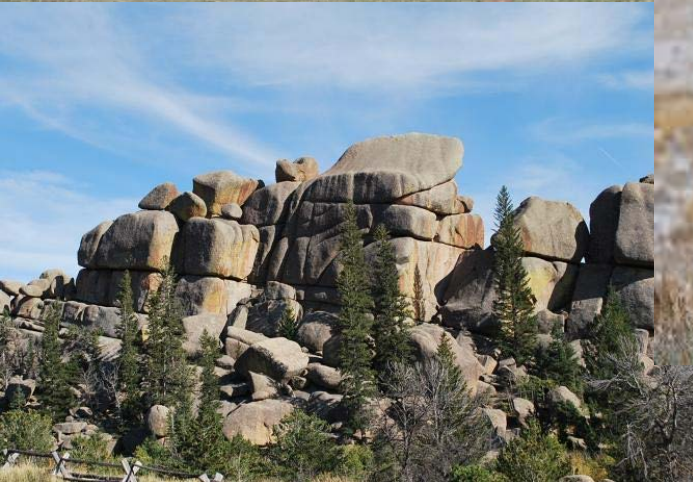
Allie Long

Chloe Storaci

University of Wyoming

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University of Wyoming Cowpokes



7200 Ft

Functional Profiles

- Using 3 classifications of functioning:
 - Mobility
 - Hand function
 - Communication

Hidecker, M. J. C., Ho, N. T., Dodge, N., Hurvitz, E. A., Slaughter, J., Workinger, M. S., . . . Paneth, N. (2012). Inter-relationships of functional status in cerebral palsy: analyzing gross motor function, manual ability, and communication function classification systems in children. *Dev Med Child Neurol*, 54(8), 737-742. doi: 10.1111/j.1469-8749.2012.04312.x

Tools

- Gross Motor Functioning Classification System (GMFCS)
- Manual Ability Classification System (MACS)
- Communication Function Classification System (CFCS)

	GMFCS ¹	MACS ²	CFCS ³
Level	Mobility	Handling objects	Communicating
I.	Walks without limitations.	Handles objects easily and successfully.	Effective sending/receiving with unfamiliar and familiar partners
II.	Walks with limitations.	Handles most objects but with somewhat reduced quality and/or spread of achievement.	Effective but slower sending/receiving with unfamiliar and familiar partners
III.	Walks using a hand-held mobility device.	Handles objects with difficulty; needs help to prepare and/or modify activities.	Effective sending/receiving with familiar partners
IV.	Self-mobility with limitations; May use powered mobility.	Handles a limited selection of easily managed objects in adapted situations.	Inconsistent sending and/or receiving with familiar partners
V.	Transported in a manual wheelchair.	Does not handle objects and has severely limited ability to perform even simple actions.	Seldom effective sending/receiving even with familiar partners

Objectives

The purpose of this research is to consider transition issues of adults and adolescents with cerebral palsy.

1. To measure CFCS inter-rater reliability among professionals and laypersons, including the person with cerebral palsy and his/her significant others.
2. To compare functional profiles of CFCS, GMFCS, and MACS levels to Rotterdam Transition Profile areas

Participants

50 adults and adolescents (24 females) with CP
U of Michigan (n=31) and McMaster U (n=19) clinics

Average Age 27 years old (Range 12 years to 76 years)
50% were 21 and under

Type of CP (% , n)

Spastic	86%	43
Dyskinetic	4%	2
Dystonic	16%	8
Choreo- Athetotic	4%	2
Ataxic	4%	2
Non-classifiable	4%	2

Limb Distribution (% , n)

Bilateral/Quad	86%	43
Unilateral/Hemi	14%	7

Participants

Education Level (Adolescents currently in school)

Some school (i.e., elementary school, middle school, junior high, high school)	56%	n=28
High school diploma / GED	20%	n=10
Attending an institution of higher education (i.e., college or university) / training program /trade school	10%	n=5
Graduate of an institution of higher education / training program / trade school	14%	n= 7

Modified Rotterdam Transition Profile

- Current Education & Employment
- Current Finances
- Current Housing
- Current Intimate Relationships
- Current Transportation
- Current Leisure/Social Activities

Donkervoort, M., Wiegerink, D. J. H. G., Van Meeteren, J., Stam, H. J., Roebroek, M. E., & Transition Research Group South West, N. (2009). Transition to adulthood: validation of the Rotterdam Transition Profile for young adults with cerebral palsy and normal intelligence. *Developmental Medicine & Child Neurology*, 51(1), 53-62. doi: 10.1111/j.1469-8749.2008.03115.x

Results (% ,n)

Level	Mobility (GMFCS)	Hand Function (MACS)	Communication (CFCS)
I	8% 4	18% 9	34% 17
II	18% 9	28% 14	28% 14
III	18% 9	16% 8	8% 4
IV	28% 14	18% 9	14% 7
V	28% 14	20% 10	16% 8

Preliminary Inter-rater Reliability

Weighted kappa
= .75
(95% CI .64-.87)

		Professional 1 CFCS Classification					
		I	II	III	IV	V	Total
Professional 2 CFCS Classification	I	16	2				18
	II		7	1	2		10
	III	1		1	2		4
	IV		2	2	3		7
	V				4	7	11
	Total	8	7	1	9	2	50

Preliminary Inter-rater Reliability

Weighted kappa
= .54
(95% CI .44-.64)

		Person with CP or Proxy CFCS Classification					Total
		I	II	III	IV	V	
Professional CFCS Classification	I	31	3		1		35
	II	11	7	2	1		21
	III		2	6			8
	IV	2	5	8	2	1	18
	V		3	4	8	3	18
	Total	44	20	20	12	4	100

Rotterdam Transition Profile

- Current Education or Work Situation (% ,n)

	All (N=50)	>21 y/o (n=25)
I am not going to school and I do not work.	34% 17	60% 15
I am going to school.	50% 25	16% 4
I am doing job training, or a work placement or co-op.	2% 1	
I am doing a paid job, or volunteer work	14% 7	24% 6

Rotterdam Transition Profile

- Current Finances (% ,n)

	All	>21 y/o
I don't have any pocket money	16% 8	4% 1
I get pocket money/an allowance from my parents/caregivers	52% 26	40% 10
I have a job on the side	4% 2	4% 1
I am financially independent (I don't need money from my family)	28% 14	52% 13

Rotterdam Transition Profile

- Current Housing (% ,n)

	All	>21 y/o
I am living with my parents/caregivers, not responsible for household activities	62% 31	44% 11
I am partly responsible for household activities	14% 7	12% 3
I am living on my own (not with my parents)	24% 12	44% 11

Rotterdam Transition Profile

- Current Intimate Relationships (% ,n)

	All	>21 y/o
I don't have any experience with dating	68% 34	48% 12
I have experience with dating	6% 3	8% 2
I am or have been involved in an intimate relationship	26% 13	44% 11

Rotterdam Transition Profile

- Current Transportation (% ,n)

	All	>21 y/o
My parents or caregivers take me where I need to go	64% 32	44% 11
My parents or caregivers arrange transportation when I need	6% 3	
I arrange it myself when I need to go somewhere	30% 15	56% 14

Rotterdam Transition Profile

- Current Leisure/Social Activities (% ,n)

	All	>21 y/o
I arrange leisure activities at home with friends	36% 16	22% 5
I arrange leisure activities with friends outside my home, only during the daytime	22% 10	22% 5
I arrange leisure activities with friends, outside my home, including in the evening	42% 19	57% 13

Correlations between Rotterdam Transition Profile and Functional Profiles

Rotterdam Areas	All ages (n=50)			>21 y/o (n=25)		
	GMFCS	MACS	CFCS	GMFCS	MACS	CFCS
Education & Employment	-.10	.07	.00	-.09	.17	-.04
Finances	-.14	-.25	-.39**	-.29	-.35	-.42*
Housing	-.22	-.26	-.34*	-.41*	-.24	-.39
Intimate Relationships	-.28*	-.35*	-.41**	-.49*	-.41*	-.50*
Transportation	-.09	-.27	-.38**	-.39	-.44*	-.69*
Leisure/Social Activities	-.36*	-.19	-.36*	-.25	.08	-.22

Spearman Correlations * p<.05 **p<.01

Conclusions

- The CFCS shows good to very good reliability with adults and adolescents with cerebral palsy
 - CFCS completed by professionals with the person/family when possible
- Communication, mobility, and hand function correlate to some transition issues
 - Will look at multivariate methods to consider the total functional profile

Future Research

- Increase the number of participants, especially in ages 30 and older, to N=90
 - Added U of New Mexico CP clinic
- Investigate differences in classifications between persons with CP and professionals
- Discuss meaningful outcomes for adults with cerebral palsy and communication disorders



Questions?