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Upper limb movements of students with cerebral palsy within a school year:

Assessment opportunities in a pedagogical scenario and some measurable changes

Thesis of Doctoral (PhD) Dissertation

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1. Introduction

1.1. Research problem

The doctoral research focuses on upper limb movements of students with physical disability (cerebral palsy, CP), caused by early lesions of the central nervous system. This is a well-defined research area of special pedagogy[1] and somatopedagogy[2] in particular. The research was based on my personal interest and motivation: as a special educational needs (SEN) teacher for students with physical disability, I often experienced inability to make the students' achievements clear, obvious and comparable to myself and to others. As rehabilitation and pedagogical rehabilitation procedures often take years, it is important for all parties involved (people with physical disability, relatives and experts) to make even subtle improvements visible and measurable, in order to boost their self-esteem and enthusiasm.

A careful literature review as well as information gathered from colleagues confirmed that hand functions are less investigated than mobility issues (Arnould et al., 2004; Wagner and Davids, 2012). Although hand functions are, to varying degrees, disturbed in all types of CP, improvements and changes in these functions over time are poorly investigated (Eliasson et al., 2006a). This is especially true in bilateral spastic (increased muscle tone) CP (Jaspers et al., 2009).

Upper limb functioning is essential in self-care, learning procedures, school and free time activities, and at work. In Hungary there is no proper assessment protocol (providing precise and functional data) used for the measurement of upper limb movements of students with CP, who attend public education.

1.2. Background, research antecedents

Cerebral palsy (CP) is a complex condition, caused by an early brain lesion. It was first described in 1862 by Little, a British orthopaedic surgeon, and was first defined by Sigmund Freud (Kavčič and Vodušek, 2005). The definition is under modification ever since, scientific disputes concerning how to describe the condition of cerebral palsy are ongoing (Rosenbaum et al., 2007; Berényi and Katona, 2014). At the beginning of the twenty-first century, new focus areas appeared in the discourse (Richards and Malouin, 2013). First, the importance of

[1] Special pedagogy is an interdisciplinary human science, dominated by pedagogy, and a multidisciplinary social science (Gordosné, 2010).

[2] „Somatopedagogy is a field of special pedagogy in the narrow sense" (Benczúrné, 1989, p.5.), „It is a complex system, in which the effects of medical, psychological and pedagogical methods, procedures and tools are achieved in harmony with the individual with a physical disability and his or her environment." (Benczúrné, 2011, p.110).

diagnosing and taking record of changes was underlined, as CP is not a static condition, but changes with age (Levitt, 2010). For rehabilitation experts, it is important to be able to assess minor changes which appear during the development procedure (Vargus Adams, 2009). Second, whatever we do, it must be in line with the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF) (Andrade et al., 2012; Lemmens et al., 2012). Third, it is essential to enable individuals with CP to self-report and self-evaluate their condition (Patrick et al., 2008; Ptyuskin et al., 2015). The latter focuses much more on environmental factors than assessment procedures used earlier.

The assessment of upper limb functioning of individuals with cerebral palsy is usually a complex procedure, consisting of a general functional classification, one or two different hand skill tests, muscle strength and tone, a functional test based on observation and/or questioning the patient about daily activities, and observation (lately instrumental analysis) of a set of motions. In some cases, complementary assessment tools are also applied to measure sensory modalities, pain and quality of life (Law et al., 2008; Fitoussi et al., 2011; Auld et al., 2012; Krebs et al., 2012). Our research design was planned in line with these theories.

2. Objective

2.1. Goals

1. The main objective of the doctoral research was to get a comprehensive understanding of upper limb functioning of children and students with CP.

During the research, we sought to investigate all internal and external factors which influence upper limb movement functioning, measure the quality of those movements,

(a) made an effort to reveal characteristic differences and similarities in the movement of students with CP and students with TD (typical development), and

(b) documented with measurable data both the changes which occurred during the school year and also rehabilitation outcomes.

A further goal was

(c) mapping connections among the different data gathered with different methods.

2. A secondary goal was thus to find and test different assessment tools for CP,

- which evaluate upper limb movements form multiple perspectives and are sensitive and proper for international comparison,

- show changes which were realised during a school year,
- are, at least, in part independent of the examiner,
- reflect the opinions and self-evaluation of individuals with CP.

2.2. Hypotheses

As regards part (a) of the research goals, we hypothesized significant differences among the sample with CP and the two control groups in their drawing movements, and in their functional self-assessment.

As regards part (b) of the research goals, significant improvement, resulting from participation in rehabilitation classes during a whole school year, was hypothesized in upper limb functioning of students with CP, which was also measurable with motion analysis and CP-specific tests.

As regards part (c), there is correlation among the tests applied for assessment, self-assessment and motion analysis.

3. Method

3.1. Sample

46 primary and secondary school students with CP (25 girls, 21 boys, mean age 13,76 years, SD 3,20, age 8-20). Sampled students were school-age students with typical intellectual development and diagnosis of spastic cerebral palsy. A further sampling criterion was that participants have at least unilateral upper limb motor disorder, and considerable discrepancy measured in the tone and functioning of the upper extremities.

The control group consisted of children and youngsters, who were not diagnosed with neurological, muscular, skeletal or joint disorders. Altogether 64 students (32 boys and 32 girls), mean age 12,31 years, SD 3,35, 8-19 years). 24 students attended the same school and had special educational needs as all of them were diagnosed with speech and language disorder (SLD). Their participation in the research emphasizes that students attending mainstream education do not form a homogenous group. Further, we wanted to find out whether learning disorders, which do not have a direct impact on understanding and carrying out the motor task, influence motor performance and motor skill learning. Literature shows that children with SLD may show varying degrees of sensory motor disorder (Getchell et al., 2010; Zelaznik and Goffman, 2010). As none of the children were diagnosed with symptoms which would refer to a physical disability, we regarded this subsample as a homogenous control group.

Control group participants were chosen keeping in mind that age and sex be similar to the CP sample. Participants were recruited in line with the general guidelines of research ethics. Exclusion criteria are detailed in the methodological part of the dissertation.

3.2. Research methodology

Assessment (see Table 1) was carried out at the beginning and end of the 2015-2016 school year (October, May), in 7 months, following a small sample size pilot study.

All students with CP participated in everyday personalized adaptive physical activity lessons in their school between the two assessments (32/2012. (X. 8.) EMMI (Ministry of Human Capacities) directive).

Children in the control group attended everyday physical education lessons. No special developmental physical activity was part of the research. Students did not practise the movements which were part of the assessment. The reason for using a wide variety of assessment tools and methods was to test them: though we had access to some, they were rarely applied in Hungary, so by testing we could decide whether or not to use these tools and methods in the future. Testing met all legislative obligations and rules.

Tools and assessment methods can be divided in three groups.

1. All participants took part in motion analysis. The task, which was completed in their school environment in standardized settings was to carry out a predefined series of movements, i.e. drawing and re-drawing a circle ten times. The series of movements was analyzed with a motion analyzer developed by our research team, the Electric Marker-based Motion Analyzer - EMMA (Lénárt et al., 2017). EMMA was designed on the basis of relevant literature and a reference appliance. During latter validation EMMA proved to be efficient in the evaluation of pre-defined motions (Lénárt et al., 2018).

2. The set of interview questions we used for self-reported evaluation of children and youths (CY) with CP, is an CP-specific ICF core set, endorsed by an international research team (Schiariti et al., 2015) to which further items were added (Lénárt and Szemenyei, 2015). ICF is a tool which was designed to be clear for all, so it uses terms which are easy to understand. This is why we chose the ICF core set for the

individuals' self-report. The set of questions with additional items was finalized after interviewing 20 respondents in a pilot study. Respondents assessed each of the 43 and 93 items, in accordance with ICF recommendations. Interviews were made in a one-to-one situation. Answers provided for both sets of interview questions were evaluated.

Table 1 Tools and assessment procedures

Field	Tool	Sample	Experimenter
Motion analysis	Electric Marker-based Motion Analyzer (EMMA)	Everyone	Research team
Self-assessment of functioning	ICF CP core sets	Everyone	Students and researchers
Clinical scales and assessment procedures		CP	
Assessor	Manual Ability Classification System (MACS), Gross Motor Classification System (GMFCS)		SEN teachers for students with physical disabilities
Outcome measure			
Motion function	Range of joint motion, muscle tone (MAS), Fugl-Meyer Assessment (FM UE), Quality of Upper Extremity Skills Test (QUEST), House thumb, Zancolli		Research team, SEN teachers of children with physical disabilities (House thumb, Zancolli)
Activities of daily living	Abilhand-Kids to CP, House classification		SEN teachers of students with physical disabilities

3. In our assessment of upper limb functions of CY with CP, we tried all relevant assessment tools and methods which the literature accounted for, and which were available and not yet widely known in Hungary (Palisano et al., 2007; McConnell et al., 2011; Thorley et al., 2012). Part of the clinical assessment scales and tools are ranking scales (Manual Ability Classification System-MACS – Eliasson et al., 2006b; Gross Motor Classification System-GMFCS – Palisano et al., 2007), others are efficient in keeping track of changes in upper limb functions over time (Table 1). All assessment, which requires that assessor and students know each other, were carried out by SEN teachers.

3.3. Data processing

During data processing protection of personal rights was respected.

Groups were characterized on the basis of the data we had gathered. Samples were tested for differences (Two-sample T-test, Analysis of Variance, Welch Test, Kruskal-Wallis test), changes which occurred over the school year were monitored (Paired T-test, Wilcoxon signed-rank test) and relations between the different assessment procedures were checked (Spearman correlation).

4. Summary of the most important findings

4.1. Sample

- Data of 37 CY with CP (21 girls, 16 boys, mean age 14,11 years, SD 3,08, 8-20 years) were processed. The control group consisted of 57 persons (33 with typical development, TD, and 22 students with speech and language disorder (SLD) (33 girls, 24 boys, mean age 12,41 years, SD 3,46, 8-19 years).
- Great improvements were detected in CP students' upper limb movement and functions. All grades of severity, with regard to gross motor movements and functionality, were represented in almost normal distribution in the sample.

4.2. Comparison of the groups

- As motion analysis shows the CP group is significantly different from both the TD and SLD control groups. There are no significant differences between the control groups (Table 2).

Table 2 Differences of the CP, TD and SLD samples with motion analysis

Group1	Group2	Mean difference	SE difference	Sig.t	Sig. M-W	Sig. d
CPa	**TDnp**	108,651	18,322	<0,001**	<0,001**	<0,001**
TDnp	SLDnp	-19,733	13,966	0,173	0,068	0,173
CPa	**SLDnp**	88,918	23,025	<0,001**	<0,001**	<0,001**

CP=cerebral palsy, TD=typically developing, SLD=speech and language disorders; p=preferred, np=non-preferred, a=more affected upper limb; SE=standard error; t=2 sample T-test, M-W=Mann-Whitney test, d=Welch test; Sig.=significant at *p<0,05, **p<0,01

- With reference to ICF core sets, CY with CP reported more severe sensory, movement, mobility and self-care limitations than the control groups (Table 3).

Table 3 Differences among the three samples with the short (N=43) ICF core set

ICF	CP-TD				CP-SLD			
b2 sensory functions	CP	16,667	Z	-4,708	CP	16,667	Z	-3,489
	TD	4,167	Sig.	**<0,001****	SLD	8,333	Sig.	**<0,001****
b7 movement functions	CP	34,375	Z	-5,174	CP	34,375	Z	-4,811
	TD	7,813	Sig.	**<0,001****	SLD	6,25	Sig.	**<0,001****
d4 mobility	CP	40,278	Z	-6,145	CP	40,278	Z	-5,68
	TD	2,778	Sig.	**<0,001****	SLD	0	Sig.	**<0,001****
d5 self-care	CP	18,75	Z	-3,19	CP	18,75	Z	-3,218
	TD	4,167	Sig.	**0,001****	SLD	2,083	Sig.	**0,001****

CP=cerebral palsy, TD=typically developing, SLD=speech and language disorders; Sig.=significant at *p<0,05, **p<0,01

4.3. Changes over the school year

- All three groups performed better during the second assessment. The most significant improvement appears in upper limb movements on the more affected side of CY with CP (Table 4).

Table 4 Changes in the 'field' variant in drawing movements of students

	Mean_2015		Mean_2016		t/Z			Sig.	
	pref.	**non-pr./inv.**	**pref.**	**non-pr./inv.**		**pref.**	**non-pr./inv.**	**pref.**	**non-pr./inv.**
CP group	45,54	**110,82**	34,763	**78,39**	**t**	1,359	**3,032**	0,183	**0,005****
					Z	**-2,718**	**-3,166**	**0,007****	**<0,001****
TD group	1,994	2,165	1,621	1,367	**t**	0,379	1,18	0,707	0,247
					Z	**-2,636**	-1,477	**0,008****	0,139
SLD group	**3,372**	21,897	**0,911**	3,725	**t**	**2,353**	1,288	**0,029***	0,212
					Z	**-2,068**	-1,547	**0,039***	0,122

CP=cerebral palsy, TD=typically developing, SLD=speech and language disorders; pref.=preferred side, non-pr/inv.=non-preferred/more involved side; t-test's: t and Wilcoxon's test: Z significant (Sig.) at *p<0,05,**p<0,01

- CP-specific tests showed significant improvements in movements of the shoulder, elbow and forearm (QUEST, FM UE, table 5), while no improvement was measured in manual functions and self-care (House Z=-1,693, p=0,09; Abilhand Z=-0,506, p=0,61).

Table 5: Changes over the school year shown by total value of QUEST and FM UE

Tests	Differences Mean	Differences SD	t	Sig.	Z	Sig.
1QUEST - 2QUEST	**-4,131**	**9,869**	**-2,546**	**0,015***	**-3,327**	**0,001****
1FM UE - 2FM UE	**-3,857**	**10,514**	**-2,402**	**0,016***	**-2,17**	**0,037***

QUEST=Quality of Upper Extremity Skills Test, FM UE=Fugl-Meyer Assessment; SD=standard deviation; t-test's: t and Wilcoxon's Z significant (Sig.) at *p<0,05,**p<0,01

4.4. Correlation among the findings

- Moderate correlation was found among motion analysis, tests and clinical movement assessments, and self-reported assessment of functions on the basis of ICF. Table 6 explains correlation between MACS and FM UE with an ICF category, together with other hand function tests and gross motor performance in the CP group.

Table 6 Relation among different test results in the CP group

Spearman correlation		d445 Hand and arm use	QuestA	QuestB	QuestC	QuestD	Quest Total	GMFCS
MACS	r^s	**0,516****	**-0,705****	**-0,575****	**-0,406***	**-0,493****	**-0,655****	**0,562****
	Sig.	**0,007**	**<0,001**	**0,001**	**0,029**	**0,007**	**<0,001**	**0,001**
FM UE	r^s	**-0,496****	**0,828****	**0,629****	**0,702****	**0,638****	**0,792****	**-0,448****
	Sig.	**0,003**	**<0,001**	**<0,001**	**<0,001**	**<0,001**	**<0,001**	**0,001**

MACS=Manual Ability Classification System; FM UE=Fugl-Meyer Assessment; QUEST=Quality of Upper Extremity Skills Test A, B, C, D subtests, Total=total value;
Sig.=significant at *p<0,05, **p<0,01

5. Discussion

5.1. Interpretation of findings

- The general objective of the research, which we fully achieved, was a multifocal assessment of upper limb functions of students with spastic cerebral palsy, in educational settings, with the participation of students and all experts involved. Several new procedures formed part of the complex assessment.

- Hypotheses regarding part (a) of the research were verified: similar to other research in this topic (Mackey et al., 2006; Fitoussi et al, 2011; Brochard et al, 2012) differences were detected in movement patterns of the CP group and the control groups, and the same applied for the assessment of functions with ICF CP core sets.

- Hypotheses concerning part (b) of the research were in part verified, as improvement in upper limb movements were not significant in all segments and functions of movement. Prange et al. (2006) in their research found similar results, while Winkels et al. (2012) account for different findings.

- Part (c) of the research was verified, as correlation among the different assessment methods was detected. The strength of the correlation was influenced by the similarities of the fields we investigated and those of the research methods we applied.

A certain part of these correlations have been investigated by other experts, but we found no references regarding others (Park et al., 2013; Schiariti et al., 2017).

Due to changes in the research environment, the original research plan was not fully carried out. Limitations of the research are discussed in detail in the dissertation. Here we underline that we worked with a small sample size, due to which probability sampling as well as grouping members of the sample according to age and the severity of CP, were impossible. It is important to note that similarly structured investigations often work with a sample size which is similar to ours (Plasschaert et al., 2019).

5.2. New findings of the research

In Hungarian practice and research novelties are:

- Efficient use of CP-specific tests for assessing upper limb movements, which had been known before the current research from international literature,
- Testing CP-specific ICF core sets,
- Development and application of a movement analyzer.

Novelties for the international research community:

- ICF-based functional assessment, based on self-assessment, and comparison of groups based on the former,
- An ICF-based, self-reported assessment of CP.

5.3. Conclusions, recommendations

- On the basis of our findings, we developed an assessment kit which can be used by SEN teachers for students with physical disability during regular pedagogical assessment. The kit includes motion analysis of a predefined movement, CP-specific upper limb tests and clinical assessment procedures, and self-assessment of functions based on ICF. The kit can be used by SEN teachers.
- The appliance we developed may be used in a standardized manner, is sensitive to individual as well as group-level differences and changes, too. It is a tinny tool, which is easy to use and has no high manufacturing costs it is therefore expected to serve a wide audience in the future.
- With a joint use of CP-specific tests and motion analyzing methods all of which are not widely known in Hungary, and with the multi-focal analysis of data we

intended to make comprehensive recommendations on their use. We suggest that FM UE and QUEST be interchangeable. We believe these easy-to-use tests be adapted in Hungary.

- The assurance of the quality of care is only possible on the basis of regular and adequate evaluations.
- ICF core sets for CP – available for all rehabilitation experts – are appropriate in the self-assessment of functions with regards both to group differences and time frames. Our plan for the future is a specific application of ICF, which would enable other members of the rehabilitation team, i.e. parents, other experts involved, to take active part in assessment.
- Our research shows that upper limb functions must be assessed together with a regular and systematic evaluation of sensory functions and the level of self-care, and improvement strategies of these fields must form part of both the work and the education of SEN teachers for students with physical disabilities.

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