The relationship of dystonia and choreoathetosis with activity, participation and quality of life in dyskinetic CP children

F. De Boeck*, **E Monbaliu, P De Cock, L Mailleux, B Dan, H Feys**

EUSUHM Annual Conference
Leuven, 2017-09-08

* Flemish Scientific Association for YHC, Leuven, Belgium
* Special Education School for Children with Motor and Multiple Disabilities, Landegem, Belgium

KU LEUVEN

Disclosure Information

Disclosure of Relevant Financial Relationships:

No financial relationships to disclose.

Disclosure of Off-Label and/or investigative uses:

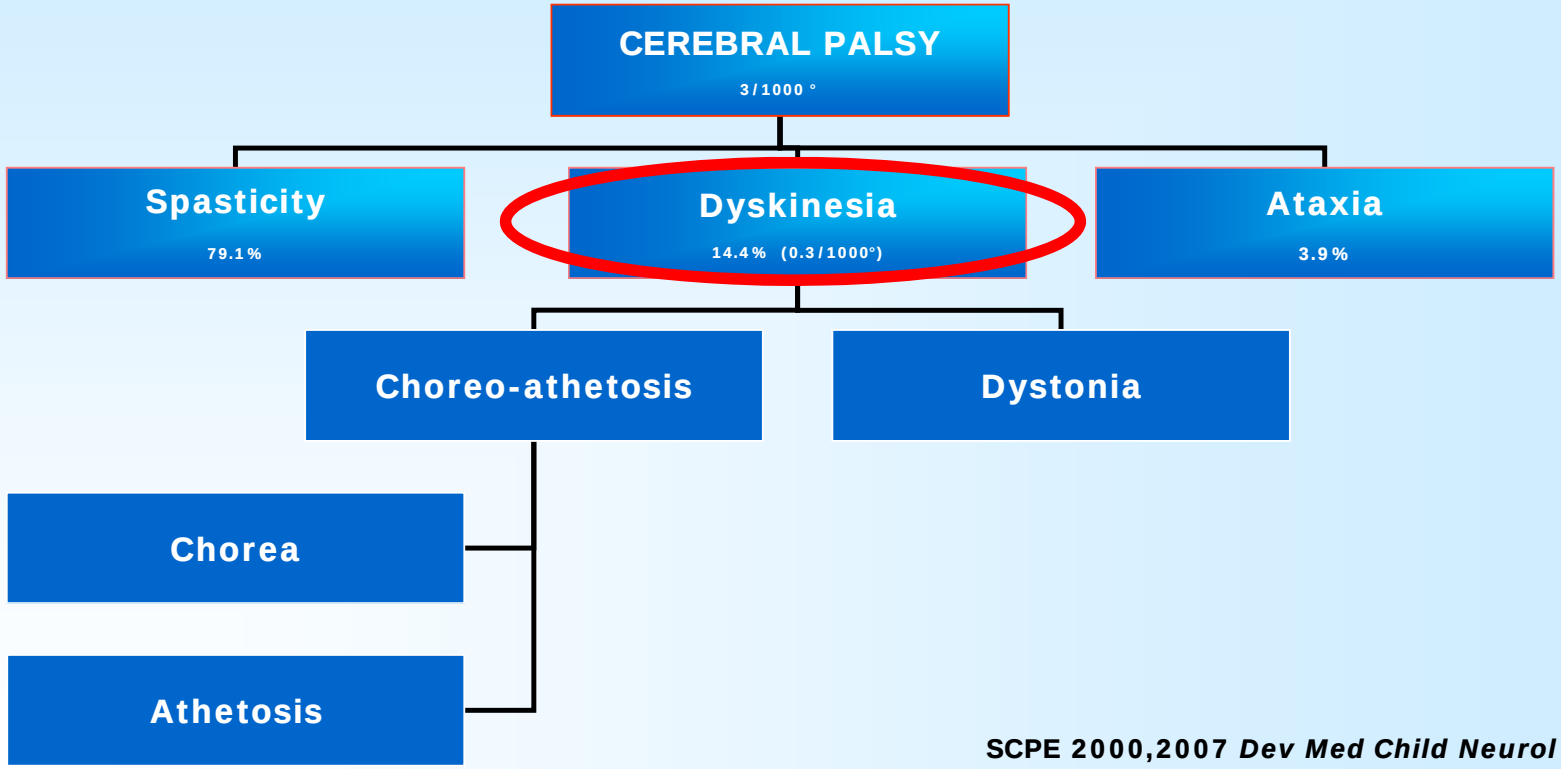
We will not discuss off label use and/or investigational use in my presentation

Introduction

Cerebral palsy *describes a group of* ***permanent disorders of the development of movement and posture****, causing* ***activity limitation****, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain.*
The motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems.

Rosenbaum et al. 2007

Introduction



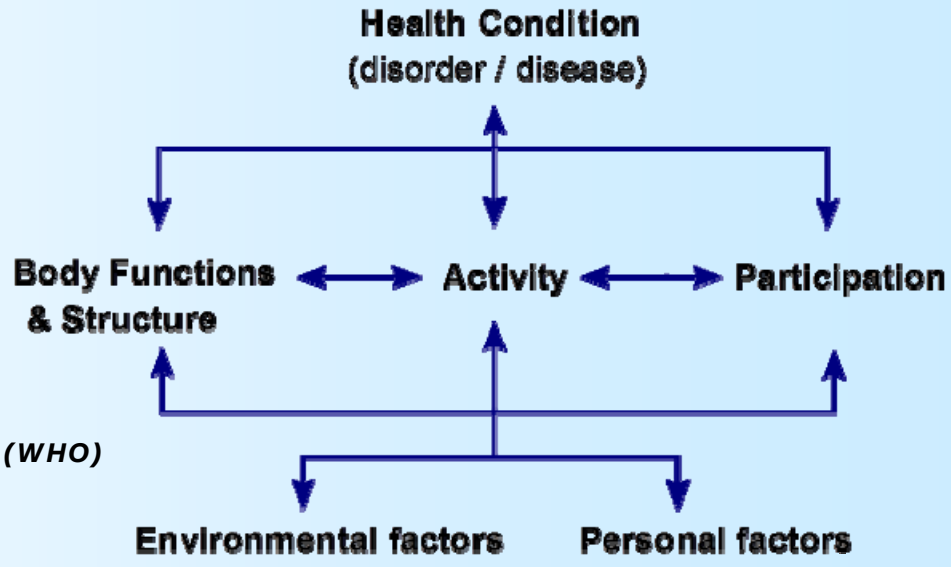
SCPE 2000,2007 *Dev Med Child Neurol*
SCPE 2005, *R&TM of the SCPE*
Bax e.a. 2006 *JAMA*
Rosenbaum e.a. 2006, 2007 *Dev Med Child Neurol*
Sanger e.a. 2010 *Mov Disord*

Introduction

Dyskinetic CP

Complex movement disorder

- Little is known about the impact of dystonia and choreoathetosis on activities and participation
- Difficult for targeted therapy



International Classification of Functioning, Disability and Health (WHO)

Objectives

To gain more insights in the relationship between the presence of **dystonia** and **choreoathetosis** & the level of **activity, participation** and **quality of life**

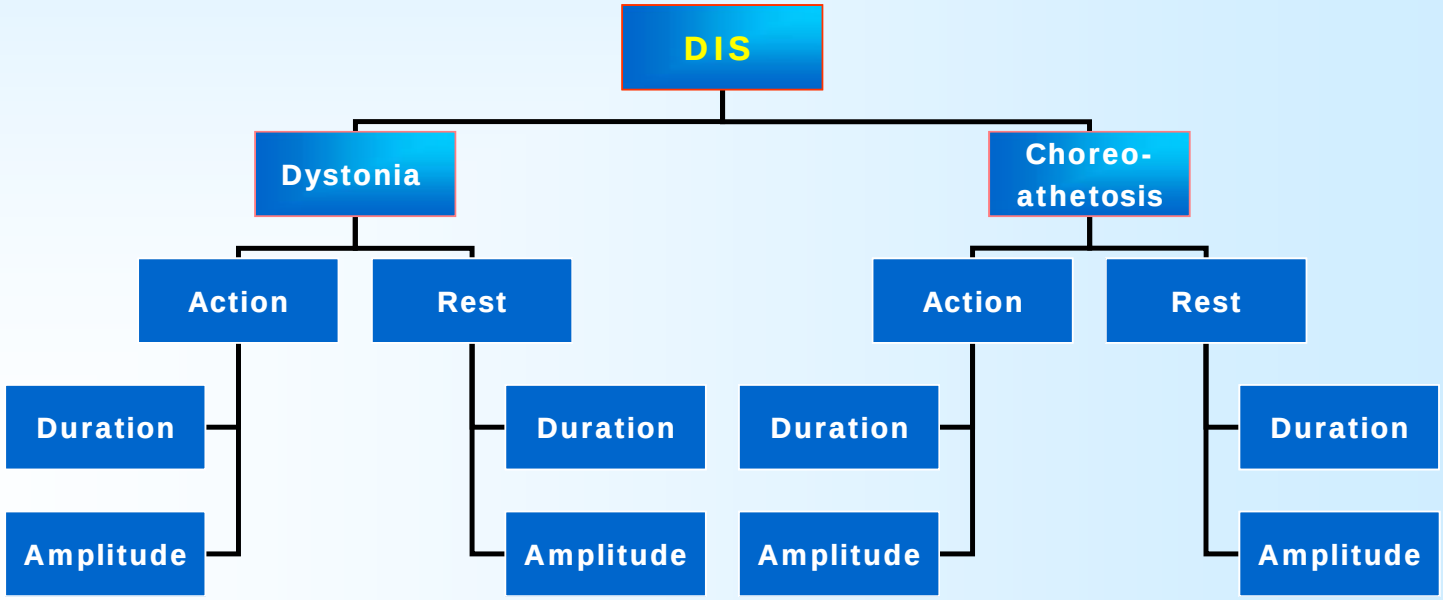
Methods : participants

Characteristics	• N=55 (30 male; 25 female) – age 5-22 yrs – Mean age=14y6mo ; SD=4y1mo
Inclusion criteria	• predominant dyskinetic CP • able to understand test instructions
Exclusion criteria	• orthopaedic or neurosurgical interventions < 12 months • spine fusion

Methods : measurement & classification

Assessment dystonia and CA : **Dyskinesia Impairment Scale (DIS)**

Monbaliu et al 2012, Dev Med Child Neurol



Methods : measurement and classification

Activity measures

Gross motor

- **Gross Motor Function Measurement**
  - Lying and rolling
  - Crawling and kneeling
  - Sitting
  - Standing
  - Walking, running and jumping
- **Functional Mobility Scale**

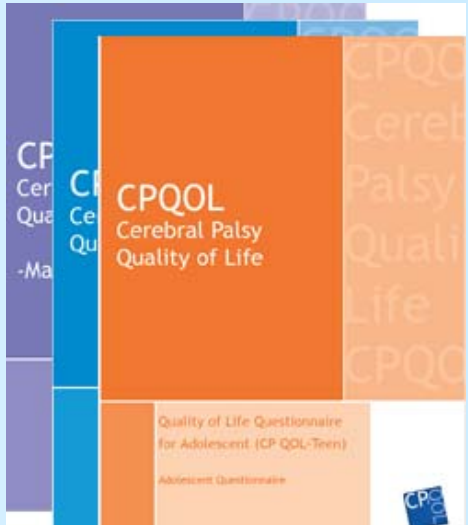
Upper limb

- **Jebson-Taylor Test of Hand Function**
  - Measures movement, speed and manual dexterity in 6 unimanual tasks
  - Expressed in seconds needed for the task execution
- **Abilhand-Kids Questionnaire**
  - Assesses manual ability on 21 manual activities
  - Perceived by parents/caretakers

Methods : measurement and classification

Participation measures

- Assessment of Life Habits Kids (LIFE-H)
  - Assesses daily activities and social roles over 12 domains
  - 0 (lowest participation) … 10 (maximal participation)
- Quality of Life Questionnaire for children with CP (CP-QOL)
  - Measures physical well-being, social well-being, school, acces to services and acceptance by others
  - 0 (lowest QOL) … 100 (maximal QOL)
  - Parent proxy-form



Results

No correlation = 0.00 < r_s < 0.25
Fair correlation = 0.25 < r_s < 0.50
Good correlation = 0.50 < r_s < 0.75
Excellent correlation = 0.75 < r_s
r_s : Spearman's rho correlation coefficient

gross motor activity measures

		Gross Motor Function r_s	Functional Mobility Scale r_s
Dystonia	Total %	-0.65**	-0.71**
	Leg %	-0.58**	-0.69**

Moderate to good relationship

		Gross Motor Function r_s	Functional Mobility Scale r_s
Choreoathetosis	Total %	-0.05	-0.27*
	Leg %	0.12	-0.14

No to very weak relationship

Results

No correlation = $0.00 < r_s < 0.25$
Fair correlation = $0.25 < r_s < 0.50$
Good correlation = $0.50 < r_s < 0.75$
Excellent correlation = $0.75 < r_s$
r_s : Spearman's rho correlation coefficient

upper limb activity measures

		Jebson-Taylor Test r_s	Abil-Hand Kids Questionnaire r_s
Dystonia	Total %	0.64**	-0.67**
	Arm %	0.76**	-0.72**

Good to excellent relationship

		Jebson-Taylor Test r_s	Abil-Hand Kids Questionnaire r_s
Choreoathetosis	Total %	-0.17	-0.09
	Arm %	0.24	-0.11

No relationship

Results

No correlation = 0.00 < r_s < 0.25
Fair correlation = 0.25 < r_s < 0.50
Good correlation = 0.50 < r_s < 0.75
Excellent correlation = 0.75 < r_s
r_s : Spearman's rho correlation coefficient

participation and quality of life

		LIFE-Habit (n=48) r_s	**CP-QOL** (n=45) r_s
Dystonia	Total %	-0.42**	-0.32**
	Mouth	-0.39**	-0.31**
	Arms	-0.60**	-0.44
	Legs	-0.23	-0.11

fair to good relationship (except for the legs)

		LIFE-Habit (n=48) r_s	**CP-QOL** (n=45) r_s
Choreoathetosis	Total %	0.13	-0.21
	Mouth	-0.14	-0.08
	Arms	0.05	-0.21
	Legs	0.14	-0.29*

No relationship

Discussion

Impact of **dystonia** on activities and participation/QOL is **higher** compared with **choreoathetosis**

Why?

- < hallmark characteristics of dystonia and CA?
- < dystonia is masking the CA?
- Further research!

Discussion

Impact of dystonia in **upper limb** and **mouth regions** on participation and QOL

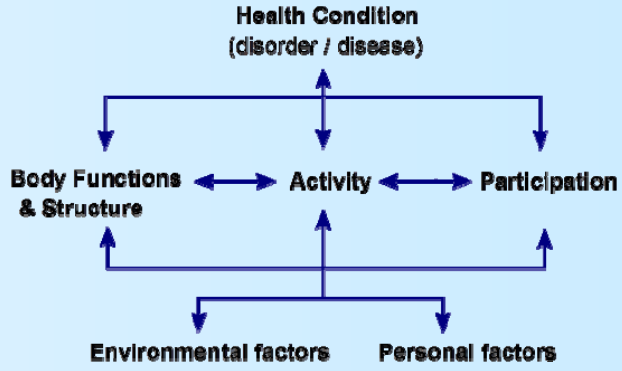
Why?

- < use of mobility aids (often operated using upper limbs)
- < communication as an important factor in participation and QOL

Conclusion

- First study to examine relationship between dystonia/CA and activities, participation and QOL
  - Importance of dystonia
  - Importance of upper limb and mouth region

- Future **targeted intervention studies** are needed : insight in importance of dystonia and CA in children with dyskinetic CP.



Thank you for your attention

KU LEUVEN