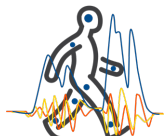


Joint webinar series on
Neurorehabilitation



Goal setting and outcome measures of interventions in pediatric rehabilitation

Annemieke Buizer
Amsterdam University Medical Center, Emma Children's Hospital, The Netherlands

1

General information about the
webinars

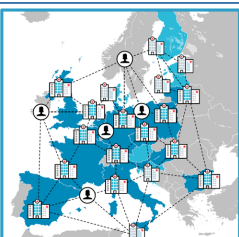
18 June 2020

- RARE neurological, neuromuscular and movement disorders
- 40-45min presentation
- 15min Q&A session at the end (please write your questions in the Q&A)
- Target audience: neurologists, residents, paediatric neurologists, geneticists and other para-medical personnel involved in patient care
- Recorded Webinar and presentation to be found at the latest 2 weeks after on: <http://www.em-md.eu/education-training/past-webinars/>
- Post-webinar survey (2-3min): satisfaction, topic/speaker ideas for next webinars

2

European Reference Network for RARE Neurological Diseases
(ERN-RND)

- Countries with Full Members
- Countries with Affiliated Partners



ERN-RND covers 6 disease groups:

1. Ataxia and HSP
2. Leukodystrophies
3. Dystonias / NBIA/Paroxysmal disorders
4. Chorea and HD
5. FTD
6. Atypical Parkinsonism

3

Speaker: Annemieke Buizer

18 June 2020

Training: MD in Rehabilitation Medicine, PhD in Pediatrics

Current position: Pediatric rehabilitation physician, full pediatric rehabilitation medicine professor of Amsterdam University Medical Centers, Emma

Affiliations: Centers, Emma

Centers of Expertise: Cerebral palsy, Leucodystrophies

Focus: I specialize in the treatment of mobility problems in children. I am project leader of Netherlands CP Register and chair of the the Dutch Academy of Childhood Disability ACD).

My research is translational and clinical, focus on interventions to improve mobility understanding underlying mechanisms of problems (from brain to muscle) in children central neurological disorders.



Amsterdam UMC

4

Webinar outline

- Role of rehabilitation in pediatric (rare) neurological diseases
- ICF-CY framework
- Pediatric rehabilitation interventions
- Goal setting for interventions
- Relevant outcome measures

Amsterdam UMC

5

Learning objectives

By the end of this webinar you will be able to:

- Define the role of rehabilitation for children with (rare) neurological diseases
- Apply the ICF-CY framework to describe functioning
- Recognize goals of rehabilitation that are important to children and their parents/caregivers
- Identify instruments to measure relevant outcomes of pediatric rehabilitation interventions

Amsterdam UMC

6

Poll 1: What is your professional background?

- Neurologist
- Neuropediatrician
- Physiatrist
- Resident
- Researcher
- Patient or patient (representative)
- Nurse
- Physiotherapist
- Occupational therapist
- Speech/language therapist
- Geneticist
- Psychologist
- Other



7

Multidisciplinary team



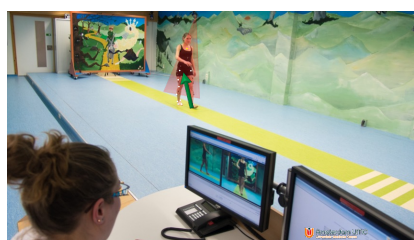
Rehabilitation team:
physiatrist, physiotherapist,
occupational therapist,
speech/language therapist,
nurse, PA, social worker,
psychologist, movement
scientists



Rehabilitation medicine:
Pediatric neurology
Pediatrics
Neurosurgery
Clinical neurophysiology
Plastic surgery
Orthopedic surgery



8



9



10

The why of my presentation

Neurologists and rehabilitation professionals can learn a lot from each other

Children with rare neurological diseases can benefit from a "generic" rehabilitation approach

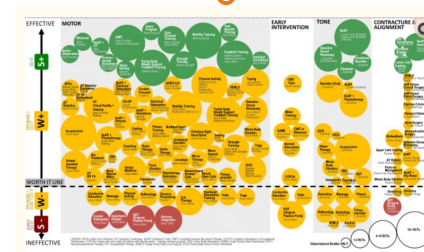
More knowledge and shared experience is needed to provide the best rehabilitation approach for each individual



Provide tools!




11



Novak et al. Curr Neurol Neurosci Rep. 2020




12



Two children: Emma and Kevin

Chronic neurological condition



13



Emma, almost 2 years old




14



Poll 2: What would rehabilitation goals be for Emma?

- Reduce spasticity
- Increase range of motion
- Increase strength
- Improve walking pattern
- To reduce pain
- To use a wheelchair
- To walk independently
- To play with friends



15

Kevin, 8 years old




16



Poll 3: What would rehabilitation goals be for Kevin?

- To reduce spasticity
- To increase range of motion
- To increase strength
- To use a wheelchair
- To walk independently
- To improve care giving
- To reduce pain
- To play with friends



17




Classification

ICD: International Classification of Disease

ICF: International Classification of Functioning, Disability and Health

Not just the cause of a disease is important, but also the effects of the disease on functioning



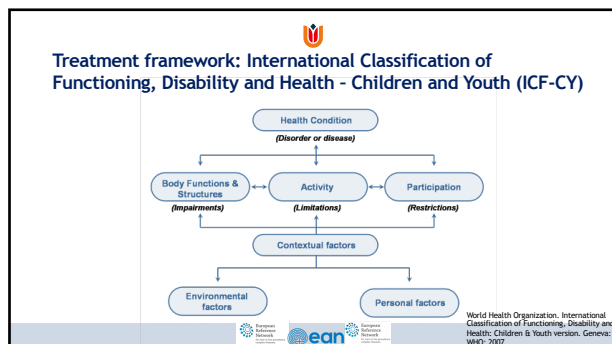
18

Poll 4: Which of the statements is true for you

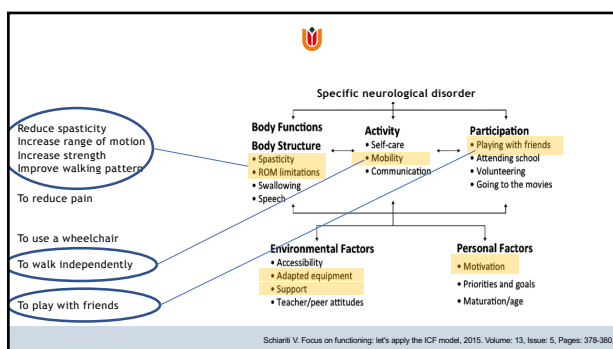
- I use the ICF model to guide treatment
- I know of the ICF, but I don't use it
- I have never heard of the ICF before now

European Reference Network for Neurological Rehabilitation (ean)

19



20



21

Emma's treatment: physiotherapy, botulinum toxin, serial casting, orthoses, walker

22

ICF-CY activity and participation domain

Items:

- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Learning and application of knowledge general tasks and demands
- Major life areas, and community (social and civic) life.

European Reference Network for Neurological Rehabilitation (ean)

23

Advantages of using the ICF-CY clinically


- Children and parents have a good understanding of the ICF activity and participation items
- Uniform language
- Structured team communication
- Stimulates a holistic approach
- Links body function/structures to activity/participation

24

Using the ICF-CY for research in pediatric rehabilitation

Primary outcome measures at activity/participation level
PROMs covering relevant domains and items

Outcomes at body function/structure level are secondary



25

Further reading

Welcome to the ICF e-learning Tool!

ICF e-learning

International Classification of Functioning, Disability and Health Core Sets for cerebral palsy, autism spectrum disorder, and attention-deficit-hyperactivity disorder

VERÓNICA SCHARITZ¹ | SOHEIL MAHDI^{2,3} | SVEN BÖLJE^{2,4}

¹ Division of Medical Sciences, University of Victoria, British Columbia, Canada; ² Division of Neurophysiology, Department of Women's and Children's Health, Centre for Neurodevelopmental Sciences (MRC), Karolinska Institute, Stockholm; ³ Centre for Pediatric Research, Stockholm County Council, Stockholm; ⁴ Child and Adolescent Psychiatry, Stockholm County Council, Stockholm, Sweden

Correspondence to: Veronica Scharitz at Division of Medical Sciences, University of Victoria, PO Box 1800 STN CSC, Victoria, BC V8W 2Y2, Canada. E-mail: vscharitz@uvic.ca


This article is copyrighted as indicated in the article. Reuse of APMIS is permitted.

26

Treatment goals in pediatric neurorehabilitation


Individual treatment goals

- Improvement of activities and participation
- Prevention of secondary problems
- Functional prognosis important to take into account



27

Cerebral palsy - Classification of mobility

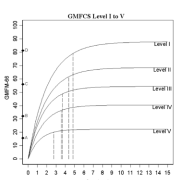


GMFCS
= gross motor function classification system

Reference: Dev Med Child Neurol 1987

28

GMFCS – functional prognosis



GMFCS Level I to V


Age (yr)

The graph shows the functional prognosis for children with cerebral palsy, categorized by GMFCS Level I to V. The Y-axis represents the Gross Motor Function Classification System (GMFCS) score, ranging from 0 to 15. The X-axis represents Age in years, ranging from 0 to 15. The curves show that children in Level I maintain the highest functional prognosis, while children in Level V have the lowest functional prognosis.

29

Example GMFCS and age

- Sits without support at 2 years of age → will walk without aids (GMFCS 1 or 2)
- No independent mobility at 2 years of age (incl rolling over) → will be fully wheelchair dependent (GMFCS 5)
- Walks with a walking aid at 5 years of age → will continue to need a walking aid (GMFCS 3 or 4)



30

Goal setting and evaluation

Outcome measures for achievement of individual goals:

- Goal Attainment Scaling (GAS)
- Canadian Occupational Performance Measure (COPM)



31

Goal Attainment Scaling (GAS)

- Problems of daily life are identified
 - Activity and participation level
- Possible outcomes (including the current situation and the desired outcome) are defined on a 5- to 7-point scale.

*Kiresuk TJ, Sherman RE. Goal attainment scaling: a general method for evaluating comprehensive community mental health programs. Community Ment Health J. 1968;4:443-453.
*Turner-Stokes L. Goal attainment scaling (GAS) in rehabilitation: a practical guide. Clin Rehabil. 2009;23:362-370.



32

Goal Attainment Scaling (GAS)

- | | |
|--|--|
| (-3):
-2: (Current level of performance)
-1:
0: (Expected level of performance after therapy)
+1:
+2: | • -3: deterioration
• -2: actual situation
• -1: less than goal
• 0: goal
• +1: more than goal
• +2: lot more |
|--|--|



33

Goal Attainment Scaling (GAS): Emma

- | | |
|---|--|
| (-3):
-2:
-1:
0:
+1:
+2: | Doesn't walk
Walks supported by parent (Current level of performance)
Walks with a walking aid inside the house, guided by parent (Expected level of performance after therapy)
Walks independently with a walking aid inside the house
Walks independently with a walking aid outside |
|---|--|

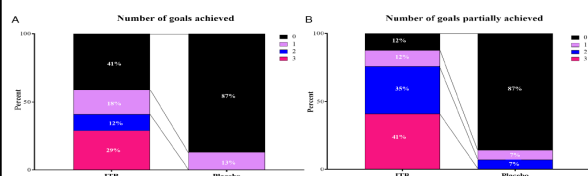


34

Results

Primary outcome measure

Goal attainment scaling - nr of goals



• Bonouvrié et al. Annals Neurol 2019

35

Canadian occupational performance measure (COPM)

- Wide variety of conditions
- All ages
- Individualized outcomes of daily life activities (i.e. self-care, productivity, and leisure).
- Goals are scored by the person with respect to importance, performance, and satisfaction, using a 10-point rating scale.
- A change of two or more points on performance and satisfaction represents a clinically important change.



Law M, et al. Can J Occup Ther 1990; 57: 62-7.
Evans IC, et al. J Rehabil Res Dev 2011; 48: 517-28

36

Kevin



37

COPM scoring

Activities	Importance	Performance	Satisfaction
I want to dress my child in an easier way	8	6	4
I want my child to be able to stand during the transfer	9	8	8
I want the changing of a diaper to be easier	7	6	5
I hope that sitting in the wheelchair is easier. (less tension in the legs, less pain)	10	5	4

38

CPCHILD QOL questionnaire

Caregivers' perspectives on:

- Health status
- Comfort
- Well being
- Ease of caregiving

CPCHILD[®]
Caregiver Priorities & Child Health Index of Life with Disabilities

Instructions

1. This questionnaire is about your child's health, comfort and well being, and about caring for his/her needs.
2. Please read the instructions carefully.
3. Please answer **all** questions by circling the number that fits best. You may write down any comments/clarifications in the space provided before each question.

For example:

Consider how each of the following activities is **usually** performed by the your child. Rate how **difficult** each of these activities were in the past 2 weeks, and **down the level of assistance** that was required to help your child perform these activities.

During the past 2 weeks, how difficult was the following:

	1	2	3	4	5	6	7	8	9	10
1. putting on "wearing footwear" (socks, shoes, sneakers, etc.)										

In the above example, the task of putting on "wearing footwear" was rated as very easy; and the child required a minimal / supervised level of assistance to put on footwear.

39

- Download CPOCHILD[™] in Acrobat format (Bahasa Malaysia)
- Download CPOCHILD[™] in Acrobat format (Brazilian Portuguese)
- Download CPOCHILD[™] in Acrobat format (Canadian French - Parent/Caregiver)
- Download CPOCHILD[™] in Acrobat format (Canadian French - Child)
- Download CPOCHILD[™] in Acrobat format (Danish)
- Download CPOCHILD[™] in Acrobat format (Dutch)
- Download CPOCHILD[™] in Acrobat format (Farsi)
- Download CPOCHILD[™] in Acrobat format (German)
- Download CPOCHILD[™] in Acrobat format (Hebrew)
- Download CPOCHILD[™] in Acrobat format (Korean)
- Download CPOCHILD[™] in Acrobat format (Norwegian)
- Download CPOCHILD[™] in Acrobat format (Spanish)
- Download CPOCHILD[™] in Acrobat format (Swedish - Parent/Caregiver)
- Download CPOCHILD[™] in Acrobat format (Swedish - Child)

<http://www.sickkids.ca/Research/CPCHILD-Questionnaire>

40

COPM scoring

Activities	Importance	Performance	Satisfaction
I want to dress my child in an easier way	8	6 → 8	4 → 8
I want my child to be able to stand during the transfer	9	8 → 6	8 → 7
I want the changing of a diaper to be easier	7	6 → 8	5 → 9
I hope that sitting in the wheelchair is easier. (less tension in the legs, less pain)	10	5 → 7	4 → 7

41

42

Patient registries incorporating individual goals and treatment outcome - example: Netherlands CP register



European Reference Network logo and ean logo

43

- Website www.cpreregister.nl



European Reference Network logo and ean logo

44

Key Points /Conclusions

Goal setting and outcome measures of interventions in pediatric rehabilitation

- Multidisciplinary teamwork
- Assessing the needs of the child/family is key
- Think ICF
- Set and evaluate individual treatment goals
- Be creative, look for opportunities and work together with child and family

European Reference Network logo and ean logo

45

Joint webinar series



THANK YOU
Next Webinar: '.....'
xxx 2020, 15-16h CET

European Reference Network logo and ean logo

46