

10-11 November 2016 | MECC Maastricht | The Netherlands



Abstract book

Congress Secretariat



Host Organization



Netherlands Society of Rehabilitation Medicine (NSRM/VRA)

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Free paper sessions

Miniymposia & workshops

0.4

0.5

0.8 0.9

Programme Overview

THURSDAY 10 NOVEMBER

1b. Free paper session1c. Free paper session

1d. Free paper session

Free paper session

08.00 - 10.00	Registration of the participants	
10.00 - 10.10	Opening: Values based rehabilitation medicine: is it about money, evidence	e or ethics? Auditorium
10.10 - 10.50	KEYNOTE LECTURE: Thomas Kelley MD MBA Value Based Healthcare: A Global Perspective	Auditorium
10.50 – 11.30	KEYNOTE LECTURE: prof. Werner Brouwer PhD <i>Value Based Rehabilitation Medicine is about money, evidence and ethics!</i>	Auditorium
11.30 – 11.50	Plenary Poster Pitch Presentations 1	Auditorium
11.50 - 13.15	Poster walk and exhibition: Networking Lunch Break	
13.15 – 14.15	Parallel Session 1: Free paper sessions	
1a.	Free paper session	Auditorium

14.15 – 15.45	Parallel Session 2: Workshops and mini-symposia	
2a.	Mini-symposium: Who is afraid of benchmarking?	0.8
2b.	Mini-symposium: Exoskeleton in rehabilitation: These suits are made for walking	Auditorium
2c.	Workshop: Adding a new dimension to post-graduate education; applying high-value cost-conscious rehabilitation medicine	0.1
2d.	Workshop: Self-management support in (pediatric) rehabilitation; from therapist to coach	0.9
2e.	Workshop: Chronic pain, valued based, evidenced based and cost effectiveness rehabilitation medicine	0.4
2f.	Mini-symposium: From Evidence-first towards Proces-oriented action research: the project 'Rehab-4-life after stroke' as case study	0.2
2g.	Mini-symposium: Valued based rehabilitation medicine = patient based rehabilitation medicine	0.5

15.45 – 16.30	Poster walk and exhibition: networking break	
16.30 - 18.00	General Assembly NSRM (VRA)	
18.00 – 19.30	Free time and bus transportation to dinner venue	
19.30 - 00.00	Dinner and music entertainment	La Caverne Geulhem

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07.30 - 08.30	Registration of the participants	
08.30 - 10.00	Parallel Session 3: Workshops and mini-symposia	
3a.		0.4
3b.	Mini-symposium: Need for integrated services for sustainable return to work after acquired brain injury	0.8
3c.	Workshop: The value of exercise: 'show me the money'.	Auditorium
3d.	Mini-symposium: Sitting-acquired pressure ulcers; how can we prevent or treat them?	0.9
3e.	Workshop: DCD-network, guideline development and consensus about parent participation	0.1
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3h.	Workshop: Consultant in Rehabilitation Medicine: what kind of doctor is that and what do they do every day?	0.3
10.00 – 10.45	Coffee break and exhibition: Networking Break	
10.45 – 12.10	Parallel Session 4: Debate and PhD thesis session	
4a.	PhD thesis session - presentations nominees of the PhD Award Rehabilitation Medicine (language ENG)	Auditorium
4b.		0.4 + 0.5
12.10 – 12.30	Plenary Poster Pitch presentations 2	Auditorium
12.30 – 13.30	Poster walk and exhibition: Networking Lunch Break	
13.30 – 15.00	Parallel Session 5: Workshops and mini-symposia	

13.30 – 15.00	Parallel Session 5: Workshops and mini-symposia	
5a.	Workshop: Psychosocial rehabilitation of people with spinal cord injury: a team approach	0.1
5b.	Mini-symposium: Treating Fatigue in MS: what's the evidence?	0.4
5c.	Mini-symposium: Putting motor learning into (neurorehabilitation) practice: A focus on analogies, cueing, and external focus of attention	Auditorium
5d.	Mini-symposium: How do we feel today, doctor?	8.0
5e.	Mini-symposium: Osseointegration in patients with lower limb amputation: Patient selection, technique, rehabilitation, pre-post evaluation and safety	0.5
5f.	Workshop: Health literacy in daily practice. Teach the teacher course: Low Health literacy - how to recognize and to supervise?	0.3
5g.	Workshop: Serious game development: take your first steps and make your own game!	0.2
5h.	Mini-symposium: Guideline development for the surgical treatment of the foot in Charcot-Marie-Tooth disease	0.9

15.45 – 16.00	Poster walk and exhibition: Networking Break	
15.45 – 16.00	Awarding best PhD thesis 2016, best presentation and best poster	Auditorium
16.00 – 16.20	KEYNOTE LECTURE: Best abstract presentation	Auditorium
16.20 – 17.00	KEYNOTE LECTURE: Prof. Gunnar Hägglund MD PhD Improved management of Cerebral Palsy by using a surveillance program an	Auditorium and quality register
17.00	Closing of the DCRM 2016	Auditorium

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Free paper sessions

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Thomas Kelley MD MBA

Thursday 10 November, 10.10 – 10.50

Value Based Healthcare: A Global Perspective

Chair: prof. Coen van Bennekom MD PhD

Summary

This presentation will consider the theory that underpins value based healthcare and the progress being made around the world with regard to the adoption of value based healthcare. Additionally, it will consider the approaches ICHOM takes to developing standard outcome sets, the implementation of outcomes measurement and the approaches and progress being made around benchmarking and collaborative learning. Perspectives will also be given around value based payment models. The presentation will end with the potential of value based healthcare in rehabilitation medicine

Biography

Education

2012-2013: MBA - University of Oxford

2004-2010: MDI; BSc (Hons) - University of Manchester

Employment

February 2016 – Present: Vice President (Business Development & Partnerships), ICHOM Head of the EMEA regional office in London: Maintain existing and develop new partnerships across the EMEA region. Responsible for ICHOM's global life science policy.

February 2015 – February 2016: Head of Europe Office, ICHOM Supervise the development of standard sets. Supervise the implementation of sets across Europe. Promote ICHOM to European payers, providers and governments.

April 2014 – January 2015: Standardization Director, ICHOM: Supervise the development of Standard Sets of outcomes out of the US and UK office.

July 2013-April 2014: Project Leader, ICHOM: Developed CAD, Cataract, Parkinson's Disease and Cleft Lip Standard Sets.

August 2010 – August 2012: Hospital Doctor, Oxford University Hospitals: Worked in acute medicine, general surgery, plastic surgery, primary care, emergency medicine and orthopaedics.



Free paper sessions

Minisymposia & workshops KEYNOTE LECTURES Abstract book DCRM 2016

Prof. Werner Brouwer PhD

Thursday 10 November, 10.50 - 11.30

Value Based Rehabilitation Medicine is about money, evidence and ethics!

Chair: prof. Coen van Bennekom MD PhD

Choices in health care are as necessary as they are difficult. Despite growing expenditures on health and health care, it is still clear that not all that is medically possible or personally desirable can be provided to all patients due to the fact that resources are limited. This leads to important medical, political and societal challenges, which can be illustrated by the recent discussions on reimbursement of expensive medicines.

Choices in line with the notion of value for money, or value based health care, are increasingly considered. Such choices are ideally based on clinical and economic evidence, and clear decision rules that may include notions of fairness.

In this presentation, I will highlight these issues and present the method of economic evaluations increasingly used in health care to assess whether specific health care interventions offer value for money. Subsequent decision rules using the outcomes of such evaluations, which also allow inclusion of notions of fairness are also explained.

I will highlight that value based health care, including value based rehabilitation medicine, requires the consideration of costs, effects as well as ethics. The Dutch decision making process and criteria for reimbursement decisions is used as illustration. The presentation also addresses some specific issues in coming to value based interventions in the context rehabilitation medicine.

Biography

Werner Brouwer (1972) is a Professor of Health Economics at and Dean of the institute of Health Policy & Management (iBMG) of the Erasmus University Rotterdam, The Netherlands. He obtained an MSc in Economics (1996) and a PhD in Health Economics (1999) at the same university. Werner is also affiliated with the institute for Medical Technology Assessment and the Erasmus School of Economics. Moreover, he is an Honorary University Professor at the Corvinus University in Budapest, Hungary.

His research focuses on the methodology of welfare economic evaluations in health care. In addition, he has performed work on the link between economic evaluation and health policy, behavioral economics and public health economics. He has published extensively on these topics (around 200 international publications) in journals like Health Economics, Journal of Health Economics, Medical Decision Making, British Medical Journal and PLoS Medicine.

Werner is an Associate Editor of Health Economics and a member of several Editorial Boards. He is a member of the Scientific Advisory Board (WAR) of the Dutch Health Care institute (ZINL), a member of subsidy-committees of the Netherlands Organization for Health Research and Development (ZonMW) and of the European Union Expert Panel on Effective Ways of Investing in Health.



Free paper sessions

Minisymposia & workshops

KEYNOTE LECTURES Abstract book DCRM 2016

Prof. Gunnar Hägglund MD PhD

Friday 11 November, 16.20 – 17.00

Improved management of Cerebral Palsy by using a surveillance program and quality register

Chair: prof. Coen van Bennekom MD PhD

Summary

The Cerebral Palsy Follow-Up Programme (CPUP) is a concept for prevention of secondary conditions in individuals with CP. It is a multidisciplinary longitudinal follow-up program that is based on clinical guidelines that simultaneously serve as a national quality registry. The program is population-based with most children in Sweden (95%) born 2000 or later with CP enrolled and recruitment of adults is underway. CPUP has also been implemented in Norway, Denmark, Iceland, Scotland, and parts of Australia.

In CP many of the secondary conditions as muscle and joint contractures, skeletal deformities, hip dislocation, and scoliosis develop slowly over time and respond best to early treatment. Through multidisciplinary follow-up and early detection of emerging complications individuals with CP can receive less complex and more effective interventions than if treatment is implemented at a later stage.

In CPUP data are collected prospectively and can provide the basis for evidence-based care and enable the development and updates of national guidelines; which, in turn, can reduce inequalities of healthcare across geographical regions. The registry also provides epidemiological profiles associated with CP and platforms for population-based research.

The possibilities and challenges to design, implement, and run a multidisciplinary secondary prevention follow-up program and quality register for individuals with CP will be described. The results achieved with CPUP will be presented.

Biography

Dr Gunnar Hägglund is professor in Pediatric Orthopaedic surgery at Lund University since 2010 and he is Consultant in Pediatric Orthopaedic surgery at University Hospital in Lund since 1998. Gunnar Hägglund was head of the Department of Orthopaedics, Lund University Hospital 1998 – 2004, and Head of the National Centre for Quality Registers in Lund 2013.

Gunnar Hägglund was one of the initiators of the CPUP in 1994 and has been the registry holder for CPUP since then. CPUP is a standardised follow-up program for children and adults with cerebral palsy. CPUP is since 2005 a National health care quality register in Sweden.



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Free paper session 1A

Chair: Aline Vrieling MD PhD

1. Differences between left and right sided neglect revisited: A large cohort study across multiple domains

<u>A.F. ten Brink MSc¹</u>, J. Verwer MSc², J.M. Biesbroek MSc², Prof. J.M.A. Visser-Meily MD PhD¹, T.C.W. Nijboer PhD¹

Introduction: It is generally accepted that left-sided unilateral spatial neglect (USN) is more severe than right-sided USN. Evidence for such a difference at a functional level is lacking. **Objectives:** To compare frequency, severity, region specificity, cognition, physical functioning, and activities of daily life (ADL) between left and right USN. Secondary aims were to compare lesion characteristics. Patients: 299 stroke patients admitted for inpatient rehabilitation. Methods: The lateralized attentional deficit was measured with cancellation and bisection tests (in peripersonal and extrapersonal space), and the Catherine Bergego scale. The MMSE, Stichting Afasie Nederland score, search organization (i.e. Best R, intersections), Motricity Index, balance, mobility and self-care were assessed. Measures were compared between left, right and no USN. Lesion locations were compared with lesion subtraction analyses. Results: Left USN (18.39%) was more frequent than right USN (10.37%). Demographic and stroke characteristics were comparable. The lateralized attentional deficit was most severe in left USN. USN in both peripersonal and extrapersonal space was more frequently left-sided in nature. Search efficiency was lower in left USN. Cognitive ability and balance were poorer in right USN. No differences were found for communication, motor function, mobility and self-care. Left USN occurred most after right hemispheric lesions, whereas no hemispheric lateralization was observed in right USN. Discussion and conclusions: Although the lateralized attention deficit is worse in left compared to right USN, consequences at the level of physical functioning and ADL are largely comparable. Clinical message: Left and right USN are both common after stroke, with comparable functional consequences.

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2. Economic evaluation of multidisciplinary rehabilitation treatment versus cognitive behavioural therapy for patients with chronic fatigue syndrome: a randomized controlled trial

<u>D.C.W.M. Vos-Vromans PhD PT</u>¹, Prof. S.M.A.A. Evers PhD², I.P.J. Huijnen PhD PT², A.J.A. Köke PhD², W.M.G.C. Hitters MD³, L.J.M. Rijnders MD¹, M. Pont MD⁴, Prof. J.A. Knottnerus PhD², Prof. R.J.E.M. Smeets MD PhD²

Introduction: Multidisciplinary rehabilitation treatment (MRT) is more effective in reducing fatigue at long-term compared to cognitive behavioural therapy (CBT) for patients with chronic fatigue syndrome (CFS) but evidence on its cost-effectiveness is lacking. **Objective:** To compare the cost-effectiveness of MRT versus CBT for patients with CFS from a societal perspective. **Method:** A multi-centre randomized controlled trial comparing MRT with CBT was conducted among patients with CFS (n=122). The societal costs (healthcare costs, patient and family costs, and costs for loss of productivity), fatigue severity, quality of life, quality-adjusted life-year (QALY), and cost-effectiveness ratios

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(ICERs) were measured over one year follow-up. The main outcome of the cost-effectiveness analysis was fatigue measured by the Checklist Individual Strength (CIS). The main outcome of the cost-utility analysis was the QALY based on the EuroQoI-5D-3L utilities. Sensitivity analyses were performed, and uncertainty was calculated using the cost-effectiveness acceptability curves and cost-effectiveness planes. **Results:** Data of 109 patients (57 MRT and 52 CBT) were analyzed. MRT was significantly more effective in reducing fatigue at 52 weeks. Mean difference in QALY between the treatments was not significant. The total societal costs were significantly higher for patients allocated to MRT (difference €5389, 95% CI: 2488, 8091). **Conclusions:**The probability of being the most cost-effective treatment is higher for MRT when taking the fatigue as primary outcome variable. Taking QALY as primary outcome, CBT has the highest probability of being the most cost-effective. **Clinical message:** To further gain cost-effectiveness, lowering the costs for MRT should be proposed and evaluated.

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3. Evaluation of a functional hand orthosis adjunct to arm-hand rehabilitation in subacute stroke patients with a severely to moderately affected hand function

J.A. Franck MSc OT¹, H.A.M. Seelen PhD¹, Prof. R.J.E.M. Smeets MD PhD²

Introduction: Stroke patients who suffer from a moderately to severely affected arm-hand have insufficient voluntary movement to participate in task-oriented training during rehabilitation. This hampers improvement in arm-hand function (AHF) and arm-hand skill performance (AHSP). Objectives: 1) evaluation of a dynamic hand orthosis combined with electrical stimulation (ES) for functional use of the moderately to severely affected arm-hand, adjunct to task-oriented training, in sub-acute stroke patients; 2) evaluation of patients' perceptions regarding hand orthosis use. Methods: Design: baseline trend-corrected single case experiment (A-B-A'). Eight patients with low or absent AHF used the orthosis combined with ES for six-weeks during task-oriented training. Outcome measures: Action Research Arm Test (ARAT), ABILHAND, Intrinsic Motivation Inventory (IMI). Results: At group level, patients improved on the ARAT (p=0.001), but not on the ABILHAND (p=0.161). Detrending for baseline trends (i.e. correcting for spontaneous recovery and/or therapy-as-usual effects) revealed that resulting ARAT scores improved significantly (median value: 13.1 points; interquartile range: [5.6, 29.2] points, p=0.002). At individual level, seven patients improved on AHF at follow-up (p<=0.020). In one patient AHF changes did not attain statistical significance. Average IMI sub-scores were between 4.6 and 6.3 (of 7), except for 'pressure/tension' (3.3). Conclusion: Patients who display little or no AHF at the start of rehabilitation may benefit from training with a dynamic hand orthosis combined with ES embedded within task-oriented training. Improvements in perceived performance, measured by the ABILHAND, remain unclear. Patients were motivated, and perceived pressure/tension related to therapy was low.

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4. The association between physical capacity and participation in persons with long-term spinal cord injury

R. Osterthun MD¹, E.J. van Overbeeke MD², F.W.A. van Asbeck MD PhD², J.J. Adriaansen MD², C.F. van Koppenhagen MD PhD³, Prof. M.W.M. Post PhD³

Introduction: Remaining physically fit and maintaining participation levels are important challenges for persons with long-term spinal cord injury (SCI). Little is known on the effect of physical capacity on participation in this patient group. Objective: To describe the association between physical capacity and participation in persons with long-term SCI in the Netherlands. Patients: 263 persons with a SCI with a time since injury of at least 10 years. Methods: A crosssectional multicentre study with the following inclusion criteria: age at injury 18-35 years, current age 28-65 years, wheelchair dependency. Information was gathered on demographics, participation levels, physical capacity, injury characteristics, secondary health conditions, functional independence and psychosocial factors. A maximum exercise test was performed to determine the physical capacity (POpeak). Participation was measured with the Restriction scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation. Results: There was a moderate correlation between a higher physical capacity and a better participation (Pearson's correlation 0.42; p<0.001). With multivariate backward regression analyses 40% of the variance of restrictions in participation could be explained. Three percent of the variance was determined by physical capacity (beta 0.209; p<0.01). Other independent determinants were gender, functional independence, self-efficacy and mental health. Conclusion and discussion: Although physical capacity only explained a small part of the variance of participation levels, a better physical capacity was independently associated with a better participation in persons with long-term SCI in the Netherlands. Clinical message:

This study supports the importance of improving and maintaining physical fitness in persons with long-term SCI.

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Free paper session 1B

Chair: Annemieke Buizer MD PhD

5. Stability of employment in adults with cerebral palsy in the long-term

<u>J.L. Benner MSc</u>¹, S.R. Hilberink PhD¹, T. Veenis MD², Prof. H.J. Stam MD PhD¹, W.M.A. van der Slot MD PhD¹, M.E. Roebroeck PhD¹

Introduction: Adults with cerebral palsy (CP) demonstrate lower employment rates compared to the general population. Little is known about long-term stability of employment. Objective: To study stability of employment in adults with CP over a 14-year period. Patients: Sixty-five Dutch adults with CP (52% male, baseline age 25.7±3.2, intellectual impairment 25%) formerly known in pediatric rehabilitation. Methods: This prospective cohort study included self-report of employment in 1996, 2000 and 2010. We assessed stability of employment rate (including sheltered work) and work hours, using GEE analyses, and compared subgroups. Results: Overall, employment rate was stable over a 14-year period (38% to 45%), but lower than in the general population (86%). Employment rates were specifically low in adults with low levels of gross motor function, bilateral CP, or intellectual impairment. In unilateral CP, employment rates tended to decrease over-time (68% to 55%). Work hours a week decreased over a 14-year period (35.0 to 31.2), specifically in females (32.3 to 23.4), a pattern similar to the general population with increasing part-time employment in females. Part of the employed persons perceived situational barriers (23%) or health problems such as pain (36%), fatique (27%); 32% had work adjustments. Discussion/conclusions: Employment rates of adults with CP are low compared to the general population, but remain stable in the long-term. Work hours decreased, especially in females. Clinical message: Support seems necessary, particularly for adults with low levels of gross motor function, bilateral CP, or intellectual impairment. Adults with unilateral CP may need support to stay employed.

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6. Long-term deterioration of perceived health and functioning in adults with cerebral palsy

<u>J.L. Benner MSc</u>¹, S.R. Hilberink PhD¹, T. Veenis MD², Prof. H.J. Stam MD PhD¹, W.M.A. van der Slot MD PhD¹, M.E. Roebroeck PhD¹

Introduction: Insight is lacking on the course of health problems and functional limitations in adults with cerebral palsy (CP) in the long-term. **Objective:** To assess longitudinal change and interrelationships of perceived health, health issues and functional level in adults with CP. **Patients:** Forty-nine Dutch adults with CP (75% spastic, 55% male, age 35-45y) formerly known in pediatric rehabilitation. **Methods:** In a prospective cohort study with 10-year and 14-year follow-up assessments, we measured self-reported perceived health, presence of health issues such as pain, fatigue, and functional level (Barthel Index, BI; ambulatory performance). Longitudinal change was estimated using GEE analyses and proportions of change, associations (OR) with perceived health were assessed using logistic regression analyses. **Results:** In the long-term, percentages of adults with CP worrying about their health (29% to 54%) and indicating impact on their activities (19% to 45%) increased, although most continued to usually feel healthy (94% to

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86%). Presence of some health issues, such as pain (58% to 71%) increased; functional level deteriorated (BI 17.1 to 16.3; walking indoors 85% to 72%). Chronic pain (OR 8.9) and severe fatigue (OR 6.0) were associated with perceived health. **Discussion and conclusions:** Perceived impact of CP increased in the long-term, with deterioration of some health issues such as pain, and functional level. **Clinical message:** Persons aging with CP face an increasing impact of their disability in the long-term, and high prevalence of pain and severe fatigue affect perceived health. The results reaffirm the importance of regular assessment in adults with CP.

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7. Vitamin D deficiency in children with motor disabilities: prevalence and determinants

E.M. Res¹, K.B. Folmer MD², A. Schölvinck MD², J.M. Voorman MD PhD², A. Beelen PhD¹

Introduction: Vitamin D is essential for bone metabolism and the immune system. Deficiency can result in muscle weakness, myalgia and rickets. In the Netherlands Vitamin D deficiency is common (30%). Children with motor disabilities may have a higher risk of vitamin D deficiency due to less sunlight exposure.

Objective: To determine the prevalence of vitamin D deficiency in children with motor disabilities and to identify potentially relating factors. **Methods:** Children from 12 to 20 years old attending a special needs school were invited. Serum 25-hydroxyvitamin D concentrations were analyzed from blood samples drawn by venapuncture. Deficiency was defined as <50 nmol/L and severe deficiency as <25 nmol/L. Factors potentially related to vitamin D status were analyzed (level of functioning, ambulation level, vitamin D supplementation, diet and sunlight exposure). **Results:** Of 130 invited children, 42 were included (32% response). Preliminary results of 38 children showed that 17 children (45%) had a vitamin D deficiency and 18% had severe deficiency (n=7). Only 12% (2/17) of the vitamin D deficiency group and 36% of the total group (15/42) supplement vitamin D daily. **Discussion and conclusions:** Prevalence of vitamin D deficiency is high under children with motor disabilities. Severe deficiency is not uncommon and only one third of the children received vitamin D supplementation. **Clinical message:** Children with a motor disability have a high risk of a mild or severe vitamin D deficiency. Daily supplement of vitamin D, enough sunlight exposure and special attention for this risk group is recommended.

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8. The Hand-Use-at-Home Questionnaire to assess spontaneous hand-use in children with unilateral paresis: evidence for validity and reliability

<u>Y. Geerdink MSc OT</u>¹, <u>M. van der Holst PT</u>², P. Aarts PhD OT¹, R. Lindeboom PhD³, J. van der Burg PhD¹, Prof. B. Steenbergen PhD⁴, D. Steenbeek MD PhD², W. Pondaag MD PhD², Prof. R.G.H.H. Nelissen MD PhD², Prof. T.P.M. Vliet-Vlieland MD PhD², Prof A.C.H. Geurts MD PhD⁵

Introduction: We developed the parent-rated Hand-Use-at-Home questionnaire (HUH) to assess the amount of spontaneous use of the affected arm/hand in daily-life activities in children with unilateral paresis, aged 3-10 years. This study describes its development and examination of the internal structure, unidimensionality, validity and test-

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retest reliability. **Patients:** Children with Unilateral Cerebral Palsy (UCP) or Neonatal Brachial Plexus Palsy (NBPP) and Typically Developing children (TD) participated. **Method:** Rasch-analysis was used to examine the rating scale and internal structure of the item-set. Test-retest reliability and construct validity was established. Intra-Class-Correlation (ICC), Standard-Error-of-Measurement (SEM) and Smallest-Detectable-Change (SDC) were calculated. Construct validity was determined by comparing HUH-scores between groups (UCP/NBPP/TD), within levels of lesion-extent in NBPP and Manual-Ability-Classification-System (MACS) levels in UCP. **Results:** The development-cohort consisted of 322 children (mean age 6.7 years, UCP:n=131/NBPP:n=191) and the validation-cohort of 315 children (Mean age 6.8 years,UCP:n=79/NBPP:n=181/TD:n=55). Eighteen hierarchically ordered bimanual items fitted a unidimensional model. HUH-scores ranged from -4.69 to 5.17 logits. Test-retest reliability was excellent (ICC=0.89). Agreement was high with a SEM=0.60 and SDC=1.66 logits. The HUH discriminated between groups (TD/NBPP/UCP): H(2)=118.985,p<0.001, supporting construct validity. HUH-scores decreased with greater lesion-extent (r=-0.5) and higher MACS-levels (r=-0.4). **Discussion/Conclusion:** The Hand-Use-at-Home questionnaire has good psychometric properties and validly quantifies the amount of spontaneous use of the affected arm/hand in children with unilateral paresis, aged 3-10 years. **Clinical Message:** The HUH questionnaire is a valuable addition to the current assessment of children with unilateral upper-limb paresis and provides clinicians with more insight in daily-life upper limb performance.

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Free paper session 1C

Chair: Agali Mert MD PhD

9. Factors associated with physical activity in adolescents and young adults with traumatic brain injury: a cross-sectional study

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Introduction: The literature on physical activity (PA) in young patients with traumatic brain injury (TBI) is contradictory. **Objective:** To determine the level of PA and its determinants in adolescents and young adults with TBI. **Patients:** Patients aged 12-40, treated between 2009-2012 in a rehabilitation center, >6 months post-TBI. **Methods:** Cross-sectional study. Apart from sociodemographic and TBI characteristics, a survey including The Activity Questionnaire for Adults and Adolescents (AQuAA; meeting Dutch PA recommendations yes/no) was administered, as well as the Checklist Individual Strength (CIS; 4 subscales, total range 20-140) measuring fatigue. Multivariate logistic regression analyses were done with age at injury, time since injury, injury severity and fatigue as independent and meeting PA recommendations as dependent variables, adjusted for age, gender and BMI. **Results:** Fifty patients were included, 22 (44%) were male, median age 22.6 years (IQR 19.9-30.3), time since injury 6.3 years (IQR 4.4-10.0) and 18 (25%) having mild TBI. Median time spent on moderate-vigorous PA was 518 minutes/week (IQR 236-1725), with 32 (64%) participants meeting PA recommendations. Nineteen (37%) had severe fatigue (CIS>40). Higher CIS subscales scores for Motivation (OR 1.14, 95%CI:1.01-1.29) and Physical Activity (OR 1.25, 95%CI:1.08-1.43), but not severity of injury (OR 0.45, 95%CI:0.13-1.65) were associated with not meeting the PA recommendations. **Conclusion:** In children and youth with TBI, physical (in)activity is associated with fatigue. **Clinical message:** Fatigue should be taken into account when developing treatment programmes promoting physical activity in children and youth with TBI.

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10. The Use of Virtual Reality in Cognitive Rehabilitation

<u>L.A. Spreij MSc¹</u>, F.J.M. Verheul MSc², S.W. Braaksma MSc³, Prof. J.M.A. Visser-Meily MD PhD¹, T.C.W. Nijboer PhD¹

Objective: Virtual Reality (VR) is one of the most popular technological advances. Due to its highly controllable and dynamic nature, VR offers many new opportunities for assessment and training of cognitive impairments after acquired brain injury (ABI). The aim of the current literature study is to describe the possibilities of VR for cognitive *assessment* and cognitive *training*, and summarize the results of recent studies that have evaluated the use of VR for cognitive rehabilitation purposes. **Search strategy:** A systematic literature search was completed using several databases in regard to studies evaluating VR-based assessments and interventions aiming to improve cognitive function after ABI.

Selection of articles: Thirteen studies appraising cognitive *assessment* en ten studies appraising cognitive *training* were included. The methodological quality of the studies was evaluated. **Evaluation of articles and results:**

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The results provide preliminary but promising evidence of the use of VR as diagnostic instrument and as training method. Positive results have been reported in *assessing* memory, neglect, executive function, and general cognitive function. The studies evaluating *training* reported significant results in improving memory, attention, executive functions, and daily cognitive activities. **Conclusion:** On the basis of this review, VR is considered potentially effective in assessing and improving cognitive function. However, the number of studies was limited, the samples sizes small, and the methodological quality moderate to low. Therefore, the results should be considered cautiously and further studies are needed to establish the effectiveness of VR in comparison to the currently used methods in cognitive rehabilitation.

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11. Physical Profile: an evidence based exercise program in rehabilitation

<u>I.J. Blokland MSc</u>¹, F.P. Groot MD², H. Houdijk PhD³

Introduction: Regular rehabilitation therapies do not always strain patients enough to improve physical fitness. Therefore Heliomare rehabilitation center introduced "Physical Profile", a structured, progressive and intensive exercise program for clinical patients. **Objective:** To describe the feasibility and the effects of '*Physical Profile'*. **Patients:** Since April 2014, 108 patients were screened for the program. 43 patients trained in the program for more than three weeks. The main reason for not starting or completing the program was early discharge. Currently 26 patients have completed the program, including pre and post-cardiopulmonary exercise test (CPET). This group consists of 15 people after stroke, 6 people with a lower limb amputation and 5 people with a spinal cord injury. **Methods:** Patients trained twice a week for one hour. Each training consisted of two high intensity interval training blocks and three strength exercises. Training was progressively adapted to the patient's fitness level. Progression was monitored at start and end of the using a CPET. **Results:** All patients showed an improved maximal power (Wpeak) after the training (median increase 18%; range [6%-80%]). The majority of patients (19/26) also improved their maximal oxygen uptake (VO2peak). The median increase in

80%]). The majority of patients (19/26) also improved their maximal oxygen uptake (VO2peak). The median increase in VO2peak was 12% (range [-13%-55%]). **Conclusion:** Due to logistic challenges and short rehabilitation stays not all patients completed the exercise program. However, the group that did follow the program showed an increase in Wmax and on average an increase in VO2peak. **Clinical message:** Despite logistic challenges, intensive physical training seems feasible and effective in a selective group of patients.

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12. Life after cardiac arrest: Cognitive impairment, natural recovery and the relation to cognitive complaints

<u>C.V.M. Steinbusch MD</u>¹, Prof. C.M. van Heugten PhD², S. Rasquin PhD³, J. Verbunt MD PhD⁴, V.R. Moulaert MD PhD³

Introduction: Cognitive impairments are common in cardiac arrest survivors. Whether subjective cognitive complaints are of predictive value on cognitive impairment is unknown. **Objective:** To investigate the prevalence of cognitive impairments at two weeks (T1), three months (T2) and 12 months (T3) after cardiac arrest. Also, to evaluate if cognitive complaints at T1 are of predictive value for cognitive impairments. **Patients and methods:** Cardiac arrest survivors were

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recruited from seven coronary care/intensive care units in the Netherlands between 2007-2010. Cognitive impairments were assessed at T1, T2 and T3 by a cognitive screening battery, including validated tests for memory, information processing speed and executive skills. Cognitive complaints were rated using the Cognitive Failure Questionnaire. Friedman and post-hoc Wilcoxon signed-ranking tests were used to test differences over time. **Results:** 141 participants were included. Cognitive impairment varied from 16-29% at T1 to 10-22% at T3. Results showed statistically significant differences on scores between T1 and T3, indicating a considerable amount of recovery, especially in the first months after cardiac arrest (p=0.000-0.010). Speed of information processing and cognitive flexibility remained impaired in 20% of the patients. 79-96% of cardiac arrest survivors with cognitive impairments did not recognize their impairments.

Conclusions: Cognitive impairments following cardiac arrest are common; 10-22% of the survivors have permanent cognitive impairments. However, most survivors with cognitive impairments do not recognize their impairments.

Clinical message: Extensive neuropsychological assessment is essential for determination of cognitive impairment, since cognitive complaints alone are not representative for actual impairments and should be part of standard care.

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Free Paper Session 1D

Chair: Janneke Stolwijk-Swüste MD PhD

13. Brain plasticity and functional recovery in low-functioning stroke patients trained with a dynamic hand orthosis: an MRI pilot study

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Introduction: Recently, dynamic hand-extension orthoses have become available that unlock new training regimes for low-functioning chronic stroke patients, for whom treatment options are very limited. To improve treatment regimes, insight is needed into brain mechanisms underlying effects of orthosis-supported rehabilitation training. Objective: To develop three well-described fMRI-protocols (imagined-grasping-task, squeeze-task, somatosensory-fingermapping-task) to be used in a larger clinical study. Patients: Healthy subjects(n=4) and patients with a severe hemiparesis (UAT-1-3,n=2) due to stroke. Methods: Initial brain imaging data associated with hand movement in orthosis-assisted(Saeboglove) and non-orthosis-assisted conditions were collected in the fMRI using a travellingwave-design, a blocked-design, and a fast-event-related-design. The patients used the Saeboglove at least ½-hour per day over a 6-week-period. Outcome measures were: a) outside the fMRI: motor performance level (Fugl-Meyer, ARAT, ABILHAND), movement time, and grip force; and b) in the fMRI: squeeze-task performance and brain activation patterns during task performance, somatosensory hand performance, and T1-weighted anatomical scans. Results: Preliminary data acquired in healthy subjects suggest that a travelling-wave-design is the most suitable for somatosensory-finger-mapping. In this design, mechanical stimulation of the fingertip starts at either the thumb or little finger, which is stimulated in short bursts, immediately followed by stimulation of the next fingers, forming a wave-stimulation. This design will now be used to investigate whether it is possible to localize the separate fingers in the somatosensory cortex in patients. Conclusion and clinical message: Insight into brain mechanisms underlying the effects of orthosis-supported rehabilitation training might help to optimise and fine-tune treatment regimen for lowfunctioning stroke patients.

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14. Hand function problems among stroke patients in the chronic phase, measured with the Michigan Hand outcomes Questionnaire (MHQ)

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Introduction: Approximately 70% of stroke survivors experience hand function problems, resulting in permanent limited function in 50%. **Objective:** To describe the occurrence of hand function problems among stroke patients in the chronic phase, by means of the Michigan Hand outcomes Questionnaire (MHQ). **Patients:** Cross-sectional study 2-5 years after hospitalization for a first-ever stroke. **Methods:** Patients completed the MHQ (6 subdomains and 1 total

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score on hand function, range 0-100, worst-best) and other questionnaires including the Short Form (SF-36) physical and mental component scale (PCS and MCS; both range 0-100, worst-best). Patient/stroke characteristics, Barthelindex (range 0-20, worst-best) after admission and length of initial hospitalization (LOH) were collected from the medical records. Association between hand functioning and other outcomes/characteristics were calculated with Pearson's correlations. **Results:** 202 patients completed the questionnaires: 125 (60%) male, mean age 64 years (SD14), mean LOH was 8.7 days(SD8.1) and mean follow-up was 36 months (SD9.9). The median MHQ total score was 79 (IQR 62-95), with 85% of respondents scoring <100. Pearson's correlation of the total MHQ score with the Barthel-index was 0.38 (p<0.001) and with LOH -0.26 (p<0.001). Correlations with PCS and MCS were 0.69 and 0.39 (both p<0.001). **Discussion and conclusions:** In the chronic phase after stroke, perceived hand function impairment is associated with initial severity of stroke and current quality of life. **Clinical message:** A substantial number of patients experiences hand function impairment, as measured by the MHQ. This is related to the quality of life in the chronic phase after stroke.

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15. Common practice in providing ankle foot orthoses for calf muscle weakness; effect on walking energy cost

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Background: Weakness of the calf muscle nearly always increases walking energy cost, which may lead to early fatigue during gait. In current clinical practice, a variety of custom-made and off-the-shell ankle-foot orthoses (AFOs) for calf muscle weakness is provided, of which the effectiveness to reduce walking energy cost has not been assured. **Objective:** This study aimed to evaluate the effectiveness of AFOs as provided for calf muscle weakness to reduce walking energy cost in patients with neuromuscular disorders. **Participants:** Twelve patients with neuromuscular disorders exhibiting calf muscle weakness who already used an AFO (uni- or bilateral) participated (9 males; mean age: 57.3 ±15.3 years; median plantar flexor MRC score: 4 (range 2-4)). **Methods:** Participants performed two 6-minute walking tests at comfortable speed with simultaneous gas analysis; one while walking with the AFO(s) + shoes, and one with shoes only. From both tests, speed (m/min), energy consumption (J/kg/min), and energy cost (J/kg/m) were derived. **Results:** Compared to shoes only, walking with AFOs significantly increased speed by 19.3% (p=0.002). Energy cost was significantly lower by 18.5% when using the AFO compared to shoes only (p=0.001). No significant difference in energy consumption was found (Table 1). **Discussion & Conclusion:** Our study shows that AFOs as prescribed for calf muscle weakness in patients with neuromuscular disorders can increase speed, which, in turn, reduces walking energy cost. **Clinical message:** Patient exhibiting calf muscle weakness should be provided with an AFO to increase speed and reduce walking energy cost.

Picture 1: https://admin.eventure-online.com/parthen-uploads/89/6DCRM/img1 294758 EhQN8sY0PL.jpg

Caption 1: * based on Brehm 2006 Arch Phys Med Rehabil; 87: 136-140;

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16. The MAC, an ecological task in addition to paper-and-pencil tasks for diagnosing neglect

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MAC is a useful addition to existing neuropsychological testing in order to diagnose neglect.

conclusions: Assessment of the MAC was feasible. Since the level of difficulty differed per corridor, it is important to evaluate each new corridor with healthy control subjects. The concurrent validity was good. **Clinical message:** The

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Introduction: One prominent deficit following stroke is visuospatial neglect. In general, neuropsychological testing is used for diagnosis. However, neglect behaviour during activities of daily life (ADL) is not always objectified with neglect tasks. Complementary tasks are therefore important. A possibility is the Mobility Assessment Course (MAC). During this multitask patients have to move through a corridor, while finding targets and reporting them. **Objective:** Aims of this explorative study were to assess the feasibility of the MAC in a rehabilitation setting, and the intern and concurrent validity. **Patients:** 74 stroke patients who were admitted for inpatient rehabilitation in De Hoogstraat and 46 healthy control subjects were included. **Methods:** We assessed standard neglect tests (i.e., object cancellation, line bisection), observations of neglect during ADL (as measured with the Catherine Bergego scale; CBS) and, in three corridors, the MAC. **Results:** 73 patients could finish the MAC. Performance of healthy control subjects differed between corridors. Patients with neglect as measured with neuropsychological tests or the CBS omitted more targets during the MAC. 18-30% of patients did not show neglect during neuropsychological tests nor the CBS, but did during the MAC. The MAC showed moderate to high correlations with neuropsychological tests and the CBS. **Discussion and**

Free Paper Session 1E

Chair: Imelda de Groot MD PhD

17. The Energetic study; effectiveness of a self-management group programme to improve social participation in patients with neuromuscular disease and chronic fatigue

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Chronic fatigue is present in more than 60% of the patients with a neuromuscular disease and can be their most disabling symptom. Chronic fatigue often coincides with low levels of physical activity and decreased social participation. We have developed a self-management outpatient rehabilitation intervention for patients with a neuromuscular disease and chronic fatigue, called *Energetic*. This multidisciplinary group programme aims to alleviate fatigue, improve physical endurance and social participation. The aim of this study was to evaluate the effectiveness of *Energetic*. A multicentre, assessor-blinded, two-armed randomised controlled trial was conducted. Assessments were made at inclusion, directly after intervention, and three and eleven months follow up. We included patients with a neuromuscular disease and chronic fatigue, and their caregivers. The participants were randomised (1:1) to either an intervention ('Energetic') or control ('usual care') group. Energetic covered four months and included four modules: 1)individually tailored aerobic exercise training; 2)education about aerobic exercise; 3)self-management training in applying energy-conservation strategies; and 4) implementation and relapse prevention in daily life. The primary outcome was the perceived performance score of the Canadian Occupational Performance Measure (COPM). Secondary outcomes included the COPM-satisfaction score, and measures of fatigue, physical endurance, activity engagement, mood, self-efficacy and caregiver-burden. Fifty-three patients were included. There was significantly more improvement on COPM-performance, COPM-satisfaction, Checklist Individual Strength (CIS), CIS subscale-fatigue and 6-Minute Walk Test for the intervention group than the control group after intervention, adjusted for baseline COPM scores, gender, work and diagnosis. These results warrant further implementation of this intervention in different settings.

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18. The wayfinding questionnaire: a clinically useful self-report assessment instrument to identify navigation complaints for stroke patients

<u>N.K. de Rooij MD PhD</u>¹, M.H.G. Claessen², I.J.M. van de Ham³, Prof. M.W. Post PhD¹, Prof. J.M.A. Visser-Meily MD PhD¹

Introduction: Navigation complaints are present after stroke, but an assessment instrument to identify these complaints is lacking. **Objective:** Study the clinical usability of the Wayfinding Questionnaire (WQ) in stroke patients. **Patients:** 158 chronic stroke patients and 64 healthy controls. **Methods:** Cross-sectional study. Both patients and controls completed

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the WQ and 3 other questionnaires on cognitive complaints, emotional complaints, and health-related quality of life (HRQoL). WQ responses (22 items) were compared for patients versus controls (discriminant validity). Effect sizes (d) and significance were calculated. WQ scores of stroke patients were dichotomized into low or normal. We compared patients with low versus normal WQ on demographics, stroke characteristics, emotional and cognitive complaints and HRQoL, and, in 78 patients, performances on navigation ability tasks in a virtual reality setting. **Results:** Patients scored lower than controls on 21/22 WQ items. In 18 items d was 0.20-0.51 (small-medium effect). The patient group with a low WQ score (n=49, 32%) consisted of lower educated patients (p=0.004), more women (p=0.013) and stated more cognitive complaints (d=0.69), more emotional problems (d=0.38 and 0.52), and lower HRQoL (d=0.40 and 0.45). This group also showed worse performance on all eight virtual reality tasks (d>0.20), and in three of these navigation ability measures d was 0.6-0.8 (medium-large effect). **Discussion and conclusions:** We found promising discriminant validity of the WQ for identifying navigation complaints in stroke patients. **Clinical message:** To identify navigation complaints after stroke we advocate the use of the WQ as an easy and valid assessment instrument.

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19. Impact of caregiver-mediated exercises to augment exercise therapy after stroke

<u>J.D.M. Vloothuis MD</u>¹, R.H. Nijland PhD¹, M. Mulder MSc^{1,2}, E. van Wegen PhD², Prof. G. Kwakkel PhD^{1,2}

Objective: To give an overview of the available evidence of caregiver-mediated exercises (CME) after stroke with respect to activities of daily living (ADL), caregiver strain, motor impairments and quality of life (Qol). **Search strategy:** A systematic search of electronic databases (a.o. CENTRAL, MEDLINE, EMBASE, SPORTDiscus) and trial registers (October 2015) was performed. **Selection of articles:** Randomized controlled trials (RCTs), comparing CME to usual care, no intervention or a control intervention, were included. **Evaluation of articles and results:** Nine RCTs about CME were included, of which six trials with 333 patient-caregiver couples could be included for meta-analysis. Significant effects in favour of CME were found for standing balance and Qol post intervention and for walking distance at follow up. In addition, two types of CME were found: trials in which CME was the core intervention and trials in which CME was employed to deliver another intervention. A sensitivity analysis with only the trials in which CME was the core intervention suggests significant favourable effects for basic ADL post intervention and for extended ADL at follow up. **Conclusion:** CME can be a valuable intervention to augment the pallet of therapeutic options for rehabilitation after stroke. Future research should determine whether CME is cost-effective, therefore an RCT (Care4Stroke) is currently being conducted. Sixty- six patients are randomly assigned to either 8 weeks of CME in addition to usual care or to 8 weeks of usual care. The primary outcomes are the mobility domain of the Stroke Impact Scale and length of stay.

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20. Quality of life of adults with Duchenne muscular dystrophy

R.F. Pangalila MD PhD¹, Prof. G.A.M. van den Bos MD PhD², Prof. H.J. Stam MD PhD³, M.E. Roebroeck PhD³

Introduction: Life expectancy of Duchenne muscular dystrophy (DMD) has risen substantially, leading to a new, severely disabled population of adults with the disease. **Objective:** We studied quality of life of this population, considering

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overall and health-related quality of life and health status. Also, we studied correlates of quality of life. **Patients:** 79 Dutch adults with DMD, aged 20-44 years. **Methods:** We performed a cross-sectional study with WHOQoL-bref and SF-36 as main outcome measures and fatigue (Fatigue Severity Scale), pain, coping (Utrecht Coping List) and self-efficacy (Global Self Efficacy Scale) among the potential correlates. **Results:** 73% of patients indicated a (very) good overall quality of life. Their scores on the health-related quality of life domains physical health, psychological health and environment were comparable to the general population, only on the domain social functioning scores were lower. On health status, scores on the physical, but not the mental domains were lower than the general population scores. Fatigue, passive reactive coping and self-efficacy were correlates of overall quality of life. **Discussion:** Adults with DMD generally perceive a good quality of life, the severe limitations notwithstanding. This should be considered when deciding on burdensome life-sustaining interventions. Further studies into the nature of and interventions for fatigue are warranted; active coping and self-efficacy should be promoted from childhood. **Clinical message:** Most adults with DMD experience a good quality of life. Some correlates of quality of life may be amenable to interventions.

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Parallel Session 2 – Mini-symposia and workshops

Thursday 10 November, 14.15-15.45

- 2a. Mini-symposium: Who is afraid of benchmarking?
- 2b. Mini-symposium: Exoskeleton in rehabilitation: These suits are made for walking
- **2c.** Workshop: Adding a new dimension to post-graduate education; applying high-value cost-conscious rehabilitation medicine
- 2d. Workshop: Self-management support in (pediatric) rehabilitation; from therapist to coach
- 2e. Workshop: Chronic pain, valued based, evidenced based and cost effectiveness rehabilitation medicine
- **2f.** Mini-symposium: From Evidence-first towards Process-oriented action research: the project 'Rehab-4-life after stroke' as case study
- **2g.** Mini-symposium: Valued based rehabilitation medicine = patient based rehabilitation medicine (NL)

2a. Mini-symposium: Who is afraid of benchmarking?

In the Netherlands, routine outcome measurement (ROM) was not required by third parties until recently. About 10 years ago, several rehabilitation centers started implementing ROM to improve the quality of rehabilitation on a voluntary basis. Based on their experiences and pressure from payers and the national government, ROM is currently being implemented on a national level for stroke and chronic pain rehabilitation. Widening the scope of ROM to all patients treated in Dutch rehabilitation is expected in the not very far future. A national databank for benchmarking is under development. In this workshop, we will briefly present our experiences with ROM in a number of Dutch rehabilitation centers. Thomas Kelley, one of the key-note speakers at this conference, director of ICHOM and an expert in ROM will reflect on these presentations from an international perspective. Ways to move forward with benchmarking in the Netherlands will be discussed with the audience.

Programme

Chair: Marcel Post

Speakers: Jorrit Slaman, Leo Roorda, Marcel Post, Coen van Bennekom, Thomas Kelley

- Introduction Marcel Post
- Routine Outcome Monitoring in Neurorehabilitation Jorrit Slaman
- Excellence in patient value. The contribution of PROMIS CATs Leo Roorda
- Using the USER in stroke rehabilitation Marcel Post
- Dutch Rehabilitation Outcome Measurement Database Coen van Bennekom
- Reflections from the international perspective Thomas Kelley

2b. Mini-symposium: Exoskeleton in rehabilitation: These suits are made for walking

As early as in the 1970s, the development of powered exoskeletons to restore locomotion in paralyzed has been reported. Initially these systems were rather bulky, not user friendly and certainly not usable in regular clinical practice. However, substantial technological advances have been made in recent years. The first commercially available have reached rehabilitation practice and first experiences are available on the use and efficacy of these assistive devices in a rehabilitation of person with spinal cord injury. These modern exoskeletons are currently used to restore walking ability. This is attempted by using the exoskeleton as a tool for gait training. Alternatively this is tried by providing the exoskeleton to patients as a permanent assistive device. Besides from potential effects on walking ability, positive effects on systemic consequences of spinal cord injury are perceived and explored. It needs to be acknowledged that current systems are far from perfect and our clinical experience is not sufficiently controlled to allow definite conclusion on their efficacy. However, technology advance rapidly and these device might develop as fast and become as common as electrical bicycles have in the last decade. So let's step into the future and explore this innovation.

Programme

Chair: Han Houdijk & Willemijn Faber

Speakers: Herman Van der Kooij, Jelle Sturkenboom, Janneke Nachtegaal, Noël/Ilse Keijsers/ van Nes, Han Houdijk, Willemijn Faber

- Introduction Han Houdijk & Willemijn Faber
- Recent and future developments in the field of powered exoskeletons an engineering perspective Herman van der Kooij
- The Cybathlon: a championship for pilots with disabilities who are using advanced assistive devices including robotic technologies Experiences from Team Delft Jelle Sturkenboom
- The exoskeleton as a training device during rehabilitation: experiences and results from Heliomare Janneke Nachtegaal
- The exoskeleton used as an orthosis: experiences and results from the Sint Maartenskliniek Noël Keijsers & Ilse van Nes

2c. Workshop: Adding a new dimension to post-graduate education; applying high-value cost-conscious rehabilitation medicine

This workshop aims to promote a critical practice-informed approach to high-value cost-conscious healthcare. Early on medical doctors learn that healthcare decisions should be evidence-based. However, there is still a lot of variation in healthcare utilization that cannot be explained by variation in patient characteristics or preferences. Moreover, we still face patient harm from over-diagnosis or overtreatment. Consequently, waste, which is anything that does not add value to the perceived health for patients, is a significant problem in our national healthcare service. At the same time, medical doctors need to adhere to the new challenges of increasing patient needs and demands, which outgrow the available resources. A practice-informed approach, already starting in the postgraduate medical education, could be the answer to these challenges medicine is facing. Processes and waste in healthcare are critically assessed from a residents' perspective in order to achieve high-value cost-conscious health care. In this workshop we will present examples and projects in rehabilitation medicine to work with. During the workshop participants work together to synthesize, translate, and present a practice-informed strategy to reduce waste and increase value of healthcare to achieve high-value cost-conscious care.

Programme

Chair: Annette van Kuijk, on behalf of the concilium VRA

Speakers: Ingrid Brands MD PhD, Wim Janssen MD PhD, Cindy Noben PhD, Janneke Hermans MD, Annette van Kuijk MD PhD, Corry den Rooyen MSc

- Welcome, Aim & Outline A. van Kuijk
- Short Structured Presentations: How is delivery of high-value cost-conscious care embedded into the new general directives for all medical specialists W. Janssen; Educational interventions to promote high-value cost-conscious care I. Brands
- Practice-informed projects: High-value cost conscious care and the practice-informed approach C. Noben;
 Sharing best practices: initiatives by residents to increase high-value cost-conscious care (in rehabilitation medicine) J. Hermans
- Workshop in small groups: 2 groups 'synthesize a practice-informed strategy to increase high-value cost
 conscious care'; 2 groups 'how to implement the proposed best practices and educational interventions to
 deliver high-value cost-conscious care'
- Plenary session: sharing workshop outcomes and closure

2d. Workshop: Self-management support in (pediatric) rehabilitation; from therapist to coach

Over the last years governmental policy in Dutch society has an increased focus on individual responsibility and participation of people with chronic conditions. In (pediatric) rehabilitation services self-management support is increasingly recognized as an essential aspect of successful interventions. Self-management support in light of the treatment process involves enlarging patients responsibility for their own process of care and partnership between individual and health care professional. In this, communication, mutual trust and respect take a central place. Specific competences of health care professionals are required to support the self-management skills of individuals, and individual empower and coach them to tune in to their needs and expectations. Experiences from the LEARN2MOVE research program in children and young adults with Cerebral Palsy have shown the importance of a coaching role of professionals during the intervention. Based on lessons learned an E-learning module has been developed focusing on improving the health care professionals' knowledge about (opportunities for) self-management support and coaching. This interactive learning platform is meant for professionals working in Dutch (pediatric) rehabilitation interested in enhancing their knowledge on self-management and coaching. The module can be used as a stand-alone learning module or integrated in more extensive face-to-face education.

Programme

Chair: Heleen Reinders-Messelink

Speakers: Johannes Verheijden, Ruud Wong Chung, Leontien Van Wely, Rita vd Berg-Emons, Heleen Reinders

2e. Workshop: Chronic pain, valued based, evidenced based and cost effectiveness rehabilitation medicine

In the post modernism context everything in which there is a demand will be considered as a possibility to be manufactured by knowledge and skills; it becomes an object of management and an object which is for sale on the market. So nowadays in the Dutch Health Care we have to consider more the cost effectiveness than the issues relating to the content. In this Workshop we will present several studies in chronic pain population in the Netherlands. Treatments of chronic pain patients will be illuminating from the ethical, economic and scientific point of view. Also interesting is that the studies is done in various Pain expert clinic in the Netherlands.

Programme

Chair: A. de Fretes

Speakers: Karlein Schreurs, Marielle Goossens, Wim Wertheim, Franca Waterschoot, Albert de Fretes

• The value of personal values in chronic pain rehabilitation - K. Schreurs

Table of content Programme overview Keynote speakers Free paper sessions Minisymposia & Poster presentations

- Alleviating symptoms in patients with chronic pain and fatigue: a large observational study of effectiveness of bio-psycho-social-spiritual rehabilitation W. Wertheim
- Social functioning in adulthood: Understanding long-term outcomes of adolescents with chronic pain or fatigue - T. Westendorp
- Dose or content? Effectiveness of pain rehabilitation programs for patients with chronic low back pain F. Waterschoot
- Costs effectiveness of rehabilitation interventions for chronic pain M. Goossens
- Discussion

2f. Mini-symposium: From Evidence-first towards Process-oriented action research: the project 'Rehab-4-life after stroke' as case study

How to organize rehabilitation care through to the home environment in a more smart and efficient way? In this minisymposium we introduce favourable concepts, methodologies and monitoring tools that may help to change the knowledge production process in rehabilitation care in an interdisciplinary and transformative way. The innovation project "Rehab-4-Life after stroke" serves as illustrative example. Rehab-4-Life is a technological and labour innovative project that makes use of a process-oriented research approach. Scientific, therapeutic, patient and contextual knowledges are thereby treated with analytical impartiality to make interactive learning and change possible A process-oriented research approach entails a number of roles for scientists, such as knowledge provider, change agent, self-reflexive scientist and process facilitator. To facilitate change multiple organizations levels need to be addressed rather than focussing on therapists as sole site of change. Rehab-4-Life is interdisciplinary of character in that it translates concepts of home- and place-making developed in migrant studies to stroke rehabilitation care. Such an open and dynamic research approach also needs more reflexive evaluation tools, enabling critical scrutiny of things that are usually taken for granted. We are working on this and hope that others will join us in this mini-symposium on our reflexive journey.

Programme

Chair: Ant. T Lettinga

Speakers: Ant Lettinga, Louise Meijering, Barbara Mierlo or colleaque

- From Evidence-first to Process-oriented action research: 'Rehab-4-Life after Stroke' as illustrative example Ant Lettinga
- Home-making after stroke: an interdisciplinary encounter between Geography and Rehabilitation Louise Meijering
- Reflexive Monitoring in Action: a dynamic and collective learning and evaluation approach Barbara van Mierlo

2g. Mini-symposium: Valued based rehabilitation medicine = patient based rehabilitation medicine

The language of this session is Dutch

This year, the Dutch Association of Medical Specialists (FMS) and The Netherlands Federation of Patients and Consumer Organizations (NPCF) will launch a public campaign on Shared Decision Making (SDM). Research suggests that SDM requires patients and professionals to be informed, motivated and engaged. Supporting people to be active participants in their care may have important implications for patient satisfaction, the extent to which people concord with treatment, relationships between patients and professionals and long-term health outcomes.

Key steps for successful SDM are:

- Health professionals and patients need to be aware that they can reach a healthcare choice together.
- Professionals give patients information about all the treatment options for their health problem.
- Patients give professionals information about their values and preferences.
- Professionals and patients reach a shared decision about the treatment option that is the best one for the patient.

We invite you to join our mini-symposium:

- to learn more about the concept of shared decision making;
- to hear from a patient her experience with shared decision making;
- to find out what you can do in helping patients share decisions;
- to discuss how we can promote shared decision making in rehabilitation medicine.

Programme

Chair: Peter Muitjens en Jolien Vervoordeldonk Speakers: Anouk Knops, Jannie Oskam, Ideke Rakers

- Shared decision making what is it about (and what not)? Anouk Knops (NPCF)
- This is how we do it! Jannie Oskam (voormalig borstkankerpatiënt)
- One or two examples of shared decision making from rehabilitation practice
- Discussion

Parallel Session 3 – Mini-symposia and workshops

Friday November, 08.30-10.00

- **3a.** Mini-symposium: The value of virtual
- 3b. Mini-symposium: Need for integrated services for sustainable return to work after acquired brain injury
- **3c.** Workshop: The value of exercise: 'show me the money'.
- **3d.** Mini-symposium: Sitting-acquired pressure ulcers; how can we prevent or treat them?
- 3e. Workshop: DCD-network, guideline development and consensus about parent participation
- **3f.** Mini-symposium: Respiratory muscle weakness in neuromuscular diseases
- **3g.** Mini-symposium: How patient values regarding their daily occupations are crucial in (cost) effective interventions
- 3h. Workshop: Consultant in Rehabilitation Medicine: what kind of doctor is that and what do they do every day?

3a. Mini-symposium: The value of virtual

Health related virtual reality and technology offer numerous new opportunities to improve quality of rehabilitation medicine. Implementation of these technologies in clinical practice is a challenge. During the DCRM 2015 the GRAIL User Group presented some do's and don'ts of this implementation. The five rehabilitation centers equipped with a GRAIL system have made significant progress in gathering evidence for the use of virtual reality and gait analysis using an instrumented treadmill for diagnostics and therapy. We are eager to share with you our first data on the added value of this type of technology in rehabilitation after stroke, amputation and cerebral palsy. Examples will include dynamically tuning lower leg prostheses, assessment of the effects of new ankle foot orthoses and prostheses on gait while walking on a slope or while tripping, as well as improving balance and preventing falls after stroke. We will also discuss the benefit of using a relatively simple and time-efficient gait analysis, as compared to clinical expertise, to judge the effect on gait parameters of rehabilitation programs aimed at improving walking skills.

Programme

Chair: Ingrid van de Port

Speakers: Juha Hijmans, Niels Jonkergouw, Noel Keijsers, Michiel Punt, Adam Booth, Ingrid van de Port

- Assessment of the effects of new ankle foot orthoses and prostheses on gait Juha Hijmans
- Quantification of prosthetic alignment for uni-lateral transtibial amputees Niels Jonkergouw
- Physical therapists' eye compared to spatiotemporal parameters to monitor gait rehabilitation in stroke patients Noel Keijsers
- Gait training to prevent falls after stroke Michiel Punt
- Effectiveness of real-time visual feedback and purposeful gaming to improve gait in children with cerebral palsy Adam Booth

3b. Mini-symposium: Need for integrated services for sustainable return to work after acquired brain injury

Every year, about 25000 people of working age acquire (non-progressive) brain injury (ABI) in the Netherlands. Gaining (paid) work again is important for people with ABI and for society when taking the costs of disability pensions into account. Return to work (RTW) after ABI is not always obvious. Special care and support is often given by different

professionals. Patients with ABI benefit by integration of their efforts. First professional that has to deal with the RTW topic of people with ABI is the neurologist. Later on the occupational physician has to deal with often complex problems of the peoples' RTW process. In addition the rehabilitation professionals of a hospital or rehabilitation centre will deal with the RTW demands of their patients. A national module focusing on work has been developed and implemented in 2015 in Dutch rehabilitation departments and centres. During this symposium, the neurologist and the occupational physician will share their experiences concerning RTW after ABI. After that, an overview of vocational rehabilitation activities provided by Dutch rehabilitation centres and rehabilitation departments of hospitals is given, illustrated by two practical examples. By focusing on the RTW topic from different perspectives, the importance of an integrated service concept is emphasized.

Programme

Chair: Coen van Bennekom

Speakers: Frank-Erik de Leeuw, Jan Konijnenburg, Judith van Velzen, Rinske Maathuis, Jacqueline Sibbel, Nicole Voet, Coen van Bennekom

- Need for integrated services for sustainable return to work after ABI Coen van Bennekom
- Long-term prognosis after stroke in young adults Frank-Erik de Leeuw
- Acquired brain injury in the occupational practice Jan Konijnenburg
- Vocational rehabilitation after acquired brain injury in rehabilitation centers and rehabilitation departments of hospitals in the Netherlands: an overview of practice variation between the institutes Judith van Velzen
- Return to work during rehabilitation Rinske Maathuis
- The added value of vocational rehabilitation during rehabilitation programmes: it works! Nicole Voet

3c. Workshop: The value of exercise: 'show me the money'

Exercise is priceless: it is good for mood, mind and health. Additionally, the economic burden of a sedentary life is large. We are tempted not to move when it rains, when discharge letters 'have to be' written or when something 'needs' our attention. Our patients are not only put back by these excuses but also face genuine barriers, such as lack of means or money. With time and experience ready at hand, the rehabilitation period is our chance to show patients how to be active and to motivate them to lead a healthy life. The introduction of the treatment modules 'inactivity' and 'insufficient physical capacity' offers the means to facilitate this. In this workshop invited speakers inspire us with an insight into the epidemiological and economic consequences of a sedentary life. They provide facts and figures that may motivate our patients and us. Once the 'table has been set', we ask patient, therapist and management to share their views on (the obstacles of) an active life. Together we come to valuable suggestions on how to put the indisputable evidence into practice. You are invited to join this dialogue.

Programme

Chair: J.A. Haisma

Speakers: A. Bolt, E.A.L.M. Verhagen, K. Valkenet, F. Hoekstra

- Welcome by A. Bolt MD Msc
- The value of investing in physical activity E.A.L.M. Verhagen PhD FECSS
- Exchange ideas on how to overcome the obstacles of an active life for our patients and ourselves.
- UMC Utrecht in Action: stimulating and integrating physical activity of patients in the hospital K. Valkenet Msc
- Costs and benefits of physical activity counseling after rehabilitation F. Hoekstra Msc
- Summary of suggestions on how to put the evidence into practice.

3d. Mini-symposium: Sitting-acquired pressure ulcers; how can we prevent or treat them?

A pressure ulcer (PU) is defined as a localized injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear. In persons with a Spinal Cord injury -but also Multiple Sclerosis and Spina Bifida- PU are both a devastating and costly problem. A PU may result in (multiple) flap surgery, hospital (re)admission and/or bed-bound periods. During seating, soft tissue, underneath the ischial tuberosity and coccyx, is exposed to pressure- and shear forces over time, resulting in internal strain and deformation. Ischemia because of prolonged compression of vascularized soft tissues leads to cell death. More direct induced damage to cells may also occur as a consequence of high mechanical loading. The following topics will be dealt with by experts from different backgrounds: The development of PU and possible risk factors will be explained from an engineering perspective. State of the art–evidence will be presented on risk factors and prevention of PU. Treatment options e.g. flap surgery will be discussed. After an open discussion we will conclude with clinical implications for treatment and prevention in daily life.

Programme

Chair: Willemijn Faber

Speakers: Willemijn Faber, Cees Oomens, Christof Smit, Linda Valent, Menno Huikeshoven, Linda Valent

- Introduction Willemijn Faber
- What are the mechanisms of development of PU? Cees Oomens
- How can we prevent PU? Christof Smit & Linda Valent
- How can we treat PU? Menno Huikeshoven
- Discussion all
- PU in daily life Linda Valent

3e. Workshop: DCD-network, guideline development and consensus about parent participation

Transition towards evidence-based approaches for children with Developmental Coordination Disorder (DCD) is an important aim of the Dutch DCD network. International experts on DCD collaborated in the European guideline for definition, diagnosis and intervention of DCD, accepted as recommendations on DCD by the European Academy of Childhood Disability (EACD; 2011). The Dutch DCD network adapted in a systematic and collaborative process these recommendations for the Dutch context. Within inter- and intra-professional expert groups the EACD recommendations were reviewed and adjusted to the Dutch context, feedback rounds on these adjustments and two national strategic conferences were organized aiming at further discussion and approval. In 2013 the Dutch adaptation of the EACD recommendations for DCD have been approved. Currently, EACD recommendations are updated and an official Dutch guideline process is in preparation. In the latter process, specific attention is paid to parental participation. In collaboration with stakeholders and in a systematic and collaborative process the updated EACD recommendations will be translated and updated into an official Dutch guideline. Involvement of perspectives of rehabilitation physicians is crucial in this process and during the workshop their input will be asked.

Chair: Jolien van den Houten

Speakers: Jolien van den Houten, Sebastiaan Severijnen, Heleen Reinders-Messelink, Parent

3f. Mini-symposium: Respiratory muscle weakness in neuromuscular diseases

Respiratory function is essential for well-being and quality of life. It is well known that respiratory muscle weakness occurs in the course of amyotrophic lateral sclerosis (ALS) and Duchenne dystrophy. Respiratory muscle weakness may occur in other neuromuscular disorders as well, such as muscular dystrophies and neuralgic amyotrophy. It is important to be aware of the possible affected respiratory function and it, therefore, should be a standard item within the consultation and examination. Respiratory function can be measured and monitored regularly when there is a suspicion and/or signs of respiratory failure. When necessary, patients should be referred to a center for home

ventilation; the timing of this referral is subject to discussion. In this mini-symposium we will address the respiratory muscle weakness in ALS, muscular dystrophies and neuralgic amyotrophy with emphasis on signs and symptoms, prognosis and treatment options. Furthermore, we will specifically pay attention to diagnostic tools to measure respiratory muscle weakness that are readily available and relatively easy to implement.

Programme

Chair: J.T. Groothuis

Speakers: J.T. Groothuis, J. Raaphorst, T.B.M. Tilanus, J.M.C. ten Broek-Pastoor

- Introduction J.T. Groothuis
- Respiratory muscle weakness in muscular dystrophies; MD, Duchenne and FSHD J. Raaphorst
- Respiratory failure in ALS: serial measurements and timing of referral to a center for home ventilation T.B.M. Tilanus
- Phrenic neuropathy in neuralgic amyotrophy J.T. Groothuis
- Hand-held spirometry: tips and tricks and drawbacks J.M.C. ten Broek-Pastoor
- Ultrasound measurements of the diaphragm: a live demonstration J. Raaphorst

3g. Mini-symposium: How patient values regarding their daily occupations are crucial in (cost) effective interventions

Background: Patient values play an important role in occupational therapy (OT) practice and are best characterized by a strong focus on the meaning of activities, role management and the context. Because different persons have different meaningful activities and roles, OT interventions are tailored to the individual patient and the social network involved. This is particularly important as the experience of 'meaning' changes when a person's capacity is reduced due to illness or injury. Over the last decade, several OT interventions for different patient groups (Parkinson's disease, dementia, chronic fatigue, cerebral palsy) have been successfully developed and evaluated. Method: An introduction on client centeredness with a focus on patient values will be followed by an overview of the theoretical background of several newly developed OT interventions. Next, presentations regarding specific patient groups will give insight in the development, evaluation and outcomes of tailored interventions. The value of using patients' wishes and needs in goal setting as well as in targeting and evaluating interventions will be discussed and therapy content and (cost)outcomes will be addressed. This mini-symposium will conclude with a synthesis of the main characteristics of the new OT interventions and a discussion of facilitators and barriers to improve value-based care.

Programme

Chair: Alexander Geurts

Speakers: Esther Steultjens, Maud Graff, Yvonne Veenhuizen, Pauline Aarts, Edith Cup, Esther Steultjens, Alexander Geurts

- Meaningful occupations and role management Esther Steultjens
- How to coach caregivers of patients with dementia in problem solving and doing their own meaningful activity beside caregiving? Maud Graff
- How to enable patients with Parkinson's disease are enabled to manage daily activities and participation? Yvonne Veenhuizen
- How Pirates (children with unilateral Cerebral Palsy) learn to perform their daily occupations? Pauline Aarts
- How to self-manage fatigue and be engaged in activities and social participation? Edith Cup
- Valued based care: Lessons learned from OT research Esther Steultjens

3h. Workshop: Consultant in Rehabilitation Medicine: what kind of doctor is that and what do they do every day?

In this workshop for medical students a strong participation of medical students in required. What do you think about the rehabilitation medicine profession? What skills are needed to become a rehabilitation professional? Fellow students from 3 universities will tell about their experiences in small educational groups. What did they see and learn in their rehabilitation encounters in medical school and on the ward in hospital and rehabilitation centre? Experienced staff will moderate the session and give clues and feedback about rehabilitation medicine. In the end we will give answers to a lot of questions about rehabilitation medicine. Everything you always wanted to know from rehabilitation medicine? please join us!

Chair: G.M.(Clemens) Rommers

Speakers: G.M.(Clemens) Rommers, Marga Tepper, Wim G.M Janssen, Medical students from University of Maastricht, University of Groningen, Erasmus University Rotterdam

Free paper sessions

Minisymposia & workshops

Parallel Session 4 – Debate and PhD Thesis Session

Friday 11 November, 10.45-12.10

4a. PhD thesis session - presentations nominees of the PhD Award Rehabilitation Medicine (language ENG)

4b. Debate: Value based medicine, is it about quality or money? (Language NL)

4a. PhD thesis session - presentations of the best PhD theses in the Netherlands: nominees of the **PhD Award Rehabilitation Medicine**

The language of this session is **English**.

During this session, the best PhD theses in the field of rehabilitation medicine in the academic year 2015-2016 in the Netherlands are presented. These dissertations are nominated by professors in rehabilitation medicine. A selection of the theses was made by the PhD Award jury. During the session the jury will select the winner from the nominees of the PhD Award 2016.

Speakers:

- Huub Creemers Optimizing quality of care for patients with ALS and their family caregivers
- Yvette Kerkum Maximizing the efficacy of ankle foot orthoses in children with cerebral palsy
- Jorik Nonnekes Balance and gait in neurodegenerative disease
- Desirée Vos Vormans Multidisciplinary rehabilitation treatment or cognitive behavioural therapy for patients with chronic fatique syndrome

Optimizing quality of care for patients with ALS and their family caregivers

This thesis focuses on patients with amyotrophic lateral sclerosis (ALS) and their most important informal caregivers. We investigated previously identified bottlenecks in complex multidisciplinary ALS care: 1) prognostication of the rate of functional decline, 2) the procurement process of assistive devices and home adaptations, 3) supportive care for patients and caregivers, and 4) caregiver strain. The overall aim was to optimize ALS care. Our systematic review showed that the current evidence on prognostic factors for functional decline is insufficient to develop a reliable prediction tool. In the procurement process of assistive devices and adaptations, patients viewed time delay and the authorities' lack of disease knowledge as the most prominent requiring improvement. The cluster RCT on case management in addition to usual ALS care showed no benefit with respect to the patients' quality of life, caregivers' strain and the quality of care. A qualitative exploration of experiences with case management identified valued aspects of case management (accessibility, home visits and ample time, proactive approach and emotional support) to be considered for implementation. We investigated potential determinants of caregiver strain and identified coping behaviour and anxiety as factors that are potentially amenable to interventions. Finally, recommendations for optimizing ALS care are presented.

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Poster presentations

Maximizing the efficacy of ankle foot orthoses in children with cerebral palsy

Yvette Kerkum

Walking is one of the most important activities in daily life, as the ability to walk enables participation in daily life activities. Although walking seems an easy task for most people, it is a delicate combination of movements of the different body parts. When a central neurological disorder, e.g. cerebral palsy (CP), results in a loss of motor control and consequently reduces the walking ability, the complexity of walking becomes apparent. In pediatric rehabilitation medicine, an important treatment goal is to acquire, maintain or improve the walking ability of children with CP. To this respect, one of the most common interventions in these patients is the use of an Ankle-Foot Orthosis (AFO). However, the efficacy of AFOs in children with CP is considered limited. Various factors that could influence AFO efficacy have been addressed, suggesting that an optimization of these features could maximize AFO efficacy. Considering the various nature of the responses to AFOs, an individual approach to optimize AFO prescription seems however essential to maximize treatment efficacy. This thesis aims to evaluate factors that enable an individual optimization of AFO prescription in order to maximize AFO efficacy in children with CP who walk with excessive knee flexion in stance.

Balance and gait in neurodegenerative disease

Jorik Nonnekes

In his thesis entitled 'Balance and gait in neurodegenerative disease: what startles tells us about motor control', Jorik Nonnekes studied balance and gait in three different groups: healthy subjects, people with hereditary spastic paraplegia (HSP), and people with Parkinson's disease. Studies in HSP and Parkinson's disease were performed to study balance and gait in two different neurodegenerative disorders that both develop slowly, but that affect different neural structures. In particular, the thesis focuses on the role of the brainstem reticular formation in impaired motor control. An important method that was used to study the brainstem reticular formation was the startle reflex and the StartReact paradigm, in which reaction times can be accelerated by a startling stimulus. The results of the performed studies suggest that dysfunction of the reticular formation contributes to gait deficits in extrapyramidal diseases (Parkinson's disease), but plays a compensatory role in gait and balance impairments in pyramidal diseases (HSP). Last but not least, Jorik presented a treatment algorithm for freezing of gait, a common gait disorder in Parkinson's disease. This treatment algorithm was published in the *Lancet Neurology*, and highlights the important role of combined pharmaceutical and non-pharmaceutical treatment strategies in the management of freezing of gait.

Multidisciplinary rehabilitation treatment or cognitive behavioural therapy for patients with chronic fatique syndrome

Desirée Vos-Vormans

Patients with chronic fatigue syndrome (CFS) experience severe fatigue, which often leads to substantial limitations in activities and participation. Annual societal costs per patient with unexplained physical symptoms are high, and underline the need to investigate new treatments and their benefits for the patient and society. One commonly used treatment that is supported by evidence of the effectiveness is cognitive behavioural therapy (CBT). Little is known about multidisciplinary rehabilitation treatment (MRT), a combination of CBT with gradual reactivation, pacing, elements of mindfulness, body awareness therapy, normalising sleep-wake rhythm and social reintegration. Therefore, a multicentre RCT trial was developed to study the effectiveness of MRT compared to CBT. The main aim of the trial was to study which treatment, CBT or MRT, was the most effective in reducing fatigue and increasing quality of life in patients with CFS. As an integral part of the RCT, the cost-effectiveness was analysed.

This study provides evidence that MRT is more effective in reducing long-term fatigue severity than CBT in patients with CFS. Regarding cost-effectiveness the results show that MRT has a high probability of being the most cost

effective, taking fatigue as primary outcome. Using the QALY as outcome, the results indicate that the CBT had a higher likelihood of being the most cost-effective.

4b. Debate: Value based medicine, is it about quality or money?

The language of this session is <u>Dutch</u>.

Dutch healthcare spending as a proportion of the GDP is the highest in Europe. This places a considerable burden on the public finances. Reducing healthcare spending in the Netherlands is one of the priorities of the Dutch Government. This leads to budget cuts of the health care institutions. In every health care institution there are the discussions about the 'mandjes'. It is a challenge: how to cut the budget and still deliver high quality health care? The rehabilitation physician is increasingly involved in the financial policy of health care institutions and also partly responsible. This can lead to a schizophrenic role of a physician: saving costs and deliver optimal quality. How do you ensure there is an optimal balance between the two?

A fierce debate will take place between two prominent rehabilitations physicians, prof. Frans Nollet MD PhD and Marc van Gestel MD. The discussion will be headed by a professional debate leader: Hans Oosterkamp. The audience is expected to participate in the discussion.

Prof. Frans Nollet MD PhD

Frans Nollet studied Medicine at the University of Amsterdam in which city he was born in 1958. He was appointed in 2003 as professor in Rehabilitation Medicine and head of the department of Rehabilitation of the Academic Medical Centre (AMC), University of Amsterdam. He is tutor for the specialty of Rehabilitation Medicine since 2003 and became one of the AMC's principal investigators in 2006. In 2015 he was appointed as Director of MOVE research institute Amsterdam, an interfacultary research institute formed by the VUmc Medical Center, the Vrije Unversiteit Faculty of Behavioural and Movement Sciences and the dentistry faculty ACTA. The aim is to integrate this institute with the AMC into a new interuniversitary research institute Amsterdam Movement Sciences, to be installed per 2017. His main hobby is road biking.

Marc van Gestel MD

Marc van Gestel (1959) is both a medical specialist in physical rehabilitation medicine (PRM) and a physician in musculoskeletal medicine since 1993. He started his career in Leypark rehabilitation center (RC) in Tilburg (which is now Libra RC) where he continued the practice of his father. His specialty lies in the field of non-neurological rehabilitation with the treatment of chronic pain as the main part. From 2000 he combines this work with a managerial function. First in Rijnlands RC in Leiden and since little over a year in Roessingh RC in Enschede, both as medical specialist PRM and managing director.

Parallel Session 5 – Mini-symposia and workshops

Friday 11 November, 13.30-15.00

- 5a. Workshop: Psychosocial rehabilitation of people with spinal cord injury: a team approach
- **5b.** Mini-symposium: Treating Fatigue in MS: what's the evidence?
- **5c.** Mini-symposium: Putting motor learning into (neurorehabilitation) practice: A focus on analogies, cueing, and external focus of attention
- **5d.** Mini-symposium: How do we feel today, doctor?
- **5e.** Mini-symposium: Osseointegration in patients with lower limb amputation: Patient selection, technique, rehabilitation, pre-post evaluation and safety
- **5f.** Workshop: Health literacy in daily practice. Teach the teacher course: Low Health literacy how to recognize and to supervise?
- 5g. Workshop: Serious game development: take your first steps and make your own game!
- **5h.** Mini-symposium: Guideline development for the surgical treatment of the foot in Charcot-Marie-Tooth disease

5a. Workshop: Psychosocial rehabilitation of people with spinal cord injury: a team approach

Rehabilitation aims to enhance functional independence, autonomy and participation of people with serious health conditions. Rehabilitation includes medical, functional and psychosocial aspects and contributions of a variety of disciplines. This workshop is based on the notion that psychosocial rehabilitation should be a team effort and not only the contribution of the psychosocial disciplines (psychology, social work, creative therapy, existential counseling) to the team. After a theoretical perspective on psychological adjustment and rehabilitation by prof. Joost Dekker, three speakers will briefly discuss psychosocial aspects in the rehabilitation process of people with spinal cord injury. All speakers will provide a statement, or a challenge, on how and what can be done to make these aspects more a responsibility and an effort of the whole rehabilitation team. These proposals will be discussed with the audience during the last part of this workshop.

Programme

Chair: Marcel Post

Speakers: Joost Dekker, Christel Van Leeuwen, Elsbeth Littooij, Tijn van Diemen, Marcel Post

- Introduction Marcel Post
- Psychological adjustment and rehabilitation Joost Dekker
- Psychosocial treatment goals Christel van Leeuwen
- Existential meaning and the rehabilitation team Elsbeth Littooij
- Psychological adaptation and the rehabilitation team Tijn van Diemen

5b. Mini-symposium: Treating Fatigue in MS: what's the evidence?

Since 2011 we have been carrying out the extensive research programme Treatment of Fatigue in Multiple Sclerosis (TREFAMS-ACE). Fatigue is one of the most often reported symptoms in Multiple Sclerosis. It often restricts social participation. The core of the TREFAMS-ACE research programme consists of three high quality Randomised Clinical Trials to investigate the effectiveness of Aerobic training, Cognitive Behavioural Therapy or Energy Conservation Management to treat fatigue in 89, 91 and 86 patients with MS respectively. In each trial, we only included patients

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with severe MS-related fatigue and measured the short (direct post intervention) and long term (after one year) effect on fatigue. We also performed a systematic review for each intervention to enable us to put the results of our RCTs into context, and studied the neurobiological working mechanisms of the interventions. The results of the three RCTs of the TREFAMS programme will make a unique and very valuable contribution to science and clinical practice on treatments for fatigue in MS, because we clearly find that one of the interventions gives better results than the other treatments.

Programme

Chair: Vincent de Groot, Jetty van Meeteren

Speakers: Lyan JM Blikman Arjan Malekzadeh, Lizanne van den Akker, Martin Heine, Vincent de Groot, Jetty van Meeteren

- What to expect from Aerobic Training? Martin Heine
- Managing of energy or something else? Lyan Blikman
- What is happening with cognitions and behaviour? Lizanne van den Akker
- What do biomarkers of MS-related fatigue tell us? Arjan Malekzadeh
- One way to treat MS-related fatigue? Vincent de Groot and Jetty van Meeteren, rehabilitation physicians

5c. Mini-symposium: Putting motor learning into (neurorehabilitation) practice: A focus on analogies, cueing, and external focus of attention

A key challenge for clinicians working within neurorehabilitation is to find the optimal way to enhance motor (re)learning of their patients. In the past decade, several supposedly distinct yet related motor learning interventions have
been hailed as being particularly effective: analogy learning, visual and auditory cueing, and learning with an external
focus of attention. Many clinicians may have heard of (and experimented with) these different approaches. Even so, it
often remains quite difficult to see how these methods relate to each other, and – more importantly – how they could
effectively incorporate them in clinical practice. Therefore, the current symposium aims to address these issues. Using
practical examples, experts on motor learning will clarify the theoretical background of analogy learning, cueing, and
external focus learning. They will discuss their potential advantages and drawbacks, and provide examples of how they
can be put to use in clinical practice. The symposium will close with a summary in which the shared mechanisms
underpinning these interventions will be highlighted, followed by a plenary discussion on successful application of
motor learning principles in neurorehabilitation. In doing so, we aim to expand clinicians' toolbox with directly
applicable knowledge of these promising motor learning interventions.

Programme

Chair: John van der Kamp

Speakers: John Van der Kamp, Melvyn Roerdink, Melanie Kleynen, Li-Juan Jie, Elmar Kal

- Motor learning in neurorehabilitation: From basic research to application in clinical practice John van der Kamp
- Cueing in gait rehabilitation: an entry point for evolving motor learning principles Melvyn Roerdink
- As easy as a walk on the beach using analogies to promotor motor relearning Melanie Kleynen & Lie-Juan Jie
- A focus on external focus in rehabilitation: what is it, why use it, and how to use it? Elmar Kal

5d. Mini-symposium: How do we feel today, doctor? (NL)

Language of this session is Dutch

Doctors are mostly highly dedicated professionals who strive for best quality of care. Unfortunately, many report that they increased work-related stress, and experience problems with combining private (family) life and career. There are many possible factors involved; Contemporary medicine can be exciting, dynamic and challenging. The financial perspective in the current Dutch healthcare system is increasingly tangible in daily practice. Many medical specialists experience an increasing workload with bureaucratic regulations, administration etcetera, leaving less time for patient care. Social demands are high and many families have 2 working parents. There has been an increase in residents (AIOS) drop out of training (in rehabilitation and other specialisms). Some have doubts, whether they will continue to work in the medical field. This is an alarming development, since much has been changed to protect residents, and residents are the young talents of our specialism. So it's about time to take a close look at the inspiration and spirit of the rehabilitation physician and residents: how do we feel today?

This mini-symposium zooms in on:

- The rehabilitation physician and residents and the challenges ahead in the future
- The importance of personal development and pro-active self-care and realization.
- And discussed issues such as:
- How can we engage and keep rehabilitation physicians and residents on board in the field of rehabilitation?
- How can we have a spirited and rich career and balance this with a private life?

Chair: Inez van der Ham

Speakers: Natasja Schijf, VVAA, more information about the other speakers will follow soon On behalf of the professional interests committee NSRM (beroepsbelangencommissie VRA)

5e. Mini-symposium: Osseointegration in patients with lower limb amputation: Patient selection, technique, rehabilitation, pre-post evaluation and safety

Approximately one third of individuals with transfemoral amputation have chronic skin problems associated with the socket of their prosthesis. Osseointegration offers many advantages in comparison to socket prosthesis. The attachment of the osseointegrated prosthesis is much more stable and this provides better walking and full range of motion of the joints. Because the prosthesis is directly attached into the bone, the prosthesis does not cause pain or skin breakdown and patients feel their prosthesis as part of their own body by natural osseoperception. In this minisymposium two different osseointegration techniques (OPRA and ILP) will be compared regarding patient selection, surgical technique, rehabilitation and pre-post evaluation. Two case reports will be presented including patient demonstration. Bone remodeling and safety issues in osseointegration will be addressed based on data from international follow up studies. Reimbursement of osseointegration by health insurance companies in relation to efficacy studies will be discussed.

Programme

Chair: F. Van der Meer

Speakers: J.M. van der Krogt, H. van de Meent, F. van der Meer, J.P.M. Frölke

- The OPRA osseointegration system: Patient selection. Technique, Rehabilitation and pre-post evaluation J.M.
 van der Krogt
- The ILP osseointegration system: Patient selection. Technique, Rehabilitation and pre-post evaluation H. van de Meent
- Two case reports (1 OPRA, 1 ILP) including patient demonstration F. van der Meer
- Safety aspects and bone remodelling J.P.M. Frölke

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5f. Workshop: Health literacy in daily practice. Teach the teacher course: Low Health literacy - how to recognize and to supervise?

For a successful treatment outcome an active and participatory role of patients is essential. Unfortunately many health professionals are unaware of the fact that a major part of the dutch population (48%) cannot comply to such requirements. Many patients do not possess the specific participatory competencies needed to manage their health. They lack reading skills or have limited perceived ability to access, understand, appraise and apply health information. Why is it important? Does lack of participatory competencies of your patient influence the communication and understanding with your patient? Does it influence the learning strategy used by the members of your rehabilitation team? Does it influence the outcome of the rehabilitation? Since 2014 second years residence of Rehabilitation Medicine learn how to recognize health literacy and how to communicate with patients with low health literacy. How to supervise your resident in Health literacy?

Chair: M. Tepper

Speakers: AHBC Schepman, W. Otto, JHM Dekker, A.J. van Dijk, M. Tepper

5g. Workshop: Serious game development: take your first steps and make your own game!

The value of serious games in rehabilitation medicine is getting solid ground, but what to do if you as a physician want to develop your own games. Where to start? How do you avoid beginners' mistakes? How do you go from an wonderful idea to an award-winning serious game where patients can benefit from? And then how do you successfully implement your game in your organization? Is it by any means ethical to have patients play games as a therapy form? In this workshop the attendees will learn about these elements in the design and implementation process of a serious game. The bonus in this workshop is that attendees will not only learn about serious games, but with the help of experts who already have been through this process before, will also make a first general outline of their own game.

Programme

Chair: Agali Mert

Speakers: Agali Mert, Riëtte Meijer, Miel Vugts

- A game you say? In rehabilition medicine? You got to be kidding me! Agali Mert
- ReValidate! the idea, development and validation of a serious game for rehabilitation Riette Meijer
- Implementing a Serious Game as a feasible component in interdisciplinary rehabilitation Miel Vugts
- Ready to develop your own game? all

5h. Mini-symposium: Guideline development for the surgical treatment of the foot in Charcot-Marie-Tooth disease

Charcot-Marie-Tooth (CMT) disease is a neuromuscular disorder affecting the muscles of the extremities. Unfortunately there is no cure for CMT, the only remedy is controlling the symptoms. There is wide variety of treatments to manage the disease ranging from physical training to surgical interventions, depending on the severity of the disease. So far, there are no guidelines for the surgical interventions of CMT. In 2014, Spierziekten Nederland in collaboration with the patient organization asked for the development of a guideline for the surgical interventions on the foot and hand. The workgroup for the guideline development consisted of rehabilitation physicians, orthopedic surgeons, paramedics and patients. The following main questions were formulated by the workgroup 1) When and for which patients is conservative treatment or surgical treatment of the feet/hands worthwhile? 2) At which stage of CMT is surgery of the feet/hands indicated in CMT patients? In this mini-symposium, the various treatment strategies for the foot will be discussed and the developed guideline presented.

Programme

Chair: Noel Keijsers / Wim Janssen

Speakers: Wim Janssen, Nicole Voet, Viola Altmann, Jan Willem Louwerens, Cheriel Hofstad, Noel Keijsers

- Short introduction of the guideline development Noel Keijsers
- Introduction and background of CMT disease and role of rehabilitation medicine Wim Janssen
- Exercise and activity training in CMT disease Nicole Voet
- Always think about all options, orthoses, shoes and operations at the same time Viola Altmann
- When and for which patients is surgical treatment recommended Jan Willem Louwerens
- What is the evidence underlying the guideline? Cheriel Hofstad

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Plenary poster presentations 1

Thursday 10 November, 11.30 - 11.50

Chair: Jorrit Meesters PhD

1. Pain rehab during puberty; working in adulthood? Work participation of adults who received pain rehabilitation during puberty; a long-term follow up

<u>D. Achten MD</u>¹, A.C.E. de Blécourt MD PhD¹, T. Westendorp MSc², H. Herweijer MD³, Prof. M.F. Reneman PhD¹

Introduction: The long-term results of an inpatient pain rehabilitation program during puberty with regards to work participation are unevaluated. Knowledge about the potential influence on future work might help to improve rehabilitation programs. Objective: To explore the long-term follow-up status of an inpatient pain rehabilitation program during puberty with regards to work participation later on in life. Patients: Potential participants: all patients who received an inpatient pain rehabilitation program 15-20 years ago because of chronic non-specific pain. Methods: Mixed-method study with semi-structured interviews and questionnaires. The semi-structured interviews contained questions about work participation in the past and present. The questionnaires measured working status, quality and quantity of the work and pain. Analyses were done according to the method of thematic analysis. **Results:** 14 adults consented to participate (12 females). Clinical status: Similar: n=9; no pain: n=2; other health complaints: n=3. Present work participation: paid work: n=10; fulltime: n=2; part-time: n=8. Self-reported quality of the work: mean 9.6 (scale 0-10). Influence of the rehabilitation program on work: don't remember; no influence; principles learned (ergonomic, energy management); complaints were gone; finishing high school; received advice on further education. Discussion and conclusions: Ten out of 14 participants are presently working, most despite pain. The influence of their pain rehabilitation program on their work participation is generally regarded as positive. Clinical message: Themes that are identified as positively (or negatively) contributing to future work participation after an inpatient pain rehabilitation program during puberty need further research.

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3. Systematic review on risk factors for musculoskeletal disorders in musicians

<u>V.A.E. Baadjou MD</u>¹, N.A. Roussel PhD², Prof. J.A.M.C.F Verbunt MD PhD¹, Prof. R.J.E.M. Smeets MD PhD³, Prof. R.A. de Bie MD PhD³

Objective: Although many musicians suffer from musculoskeletal disorders, aetiological factors are unclear. Objective was to systematically search for and synthesize the best available evidence on risk factors for musculoskeletal disorders in musicians. **Search strategy:** A database search was performed in PubMed, EMBASE, CINAHL, Pedro, OTseeker, Psychinfo. A manual search was conducted in the journals Medical Problems of Performing Artists and Psychology of Music. **Selection of articles:** Studies with an objective to investigate determinants associated with playing-related musculoskeletal disorders were included. Papers were selected based on adequacy of statistical

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methods for the purpose of the study. Search, first screening and selection were performed by one author. Two reviewers independently performed the final selection using full text reports and methodological quality assessment. **Evaluation of articles and results:** One case-control and fourteen cross-sectional studies were included. Methodological quality was in general low. Large heterogeneity existed in study design, population, measurement of determinant and outcome, and analysis techniques. Data were presented descriptively. Consistent results were found indicating that previous musculoskeletal injury, music performance anxiety, high levels of stress, and being a female playing a stringed instrument seemed to be associated with more musculoskeletal disorders. Influence over or support at work, orchestra category/ status, exercise behaviour and cigarette smoking seemed to be unrelated with musculoskeletal disorders. No conclusions could be made on causality, as the current data only represent cross-sectional associations. **Conclusions:** Because of lack of prospective studies, no causal relations could be identified in the aetiology of (playing-related) musculoskeletal disorders in instrumental musicians.

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5. Quality of life, burden and satisfaction with care of caregivers of spinal cord injured patients during and 1.5 years after active rehabilitation

<u>A.P.M. Backx MD</u>¹, A.I.F. Spooren PhD², H.M.H. Bongers-Janssen MD¹, H. Bouwsema PhD^{3,4}

Introduction and objective: little is known about the course of burden, quality of life (QoL) and satisfaction with care in European caregivers of spinal cord injured (SCI) patients. The objective of this study was to examine these issues in Dutch caregivers. Participants: adult caregivers(n=37) taking care of patients with recently acquired SCI (AIS-A:12/AIS-B:1/AIS-C:7/AIS-D:17, 28.9% tetraplegic). Method: longitudinal, prospective cohort study. Caregiver Strain index (CSI), Short Form-36 (SF-36) and Caregivers' Satisfaction with (Stroke) Care Questionnaire (C-SASC) were administered at start active rehabilitation (T1), cessation of active rehabilitation (T2), 8 weeks follow-up (T3), 6 months (T4) and 18 months follow-up (T5, currently being assessed). Results: during rehabilitation 21 caregivers (57%) experienced high levels of burden (mean total CSI-score:6.9±2.9), which significantly decreased during follow-up (mean total CSI-score T5:4.5±3.5, p=0.015). Initial low scores on QoL improved significantly in the SF-36 domains 'social-role-functioning' (score T1: 54.7, T3: 76.0, p=0.003), 'emotional-role-functioning' (T1: 51.9, T4: 90.7, p=0.007), 'mental health' (T1: 57.3, T3: 71.8, p=0.028) and 'vitality' (T1: 49.1, T5: 68.7, p=0.033). Moderate-strong negative correlations were found between total CSI-score and 'social-role-functioning' (at T1-T2-T3-T4), 'emotional-role-functioning' (all time points), 'mental health' (T2-T3-T4-T5) and 'vitality' (all time points) with p-values < 0.041. Overall satisfaction with care of caregivers was good (C-SASC: median 3,IQR[3,4]) and stable over time (p=0.31). Discussion and conclusions: this study provides evidence for caregivers of SCI-patients adapting to initial high levels of strain. Clinical message: every clinician working with both SCI-patients and caregivers should be vigilant as to possible high burden and low QoL of caregivers during rehabilitation.

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7. Musculoskeletal pain of the non-affected arm, neck and back in patients with brachial plexus injury

J.M. van Bodegom MD MSc, Prof. C.K. van der Sluis MD PhD, Prof. K. Postema MD PhD

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Introduction: Brachial plexus injury (BPI) has restricting effects on arm function. Therefore, the non-affected arm is used more to perform tasks unilaterally, and neck and upper back are used asymmetrically. **Objectives:** To assess the prevalence of musculoskeletal pain in non-affected arm, neck and back compared with controls. To investigate factors predicting pain and disability. **Participants:** Adults with >1 year existing unilateral BPI. Healthy controls. **Methods:** Questionnaire with personal, social (work), coping and pain specific questions, Disability of Arm, Shoulder, Hand (DASH), and RAND-36 (health perception, mental health, pain). Statistical tests: t-tests, Chi-square, logistic regression. **Results:** Seventy-nine patients (mean age: 51yr; 65% men) and 114 controls (mean age: 50yr; 63% men) participated. Point prevalence of pain (<4 weeks) in the BPI-group did not differ (p=0.092), while the year prevalence was higher (p=0.008) compared to controls. Within the BPI-group patients with pain scored lower on the RAND health and mental questions (p=0.043 and p=0.045, respectively), time since BPI was longer (p=0.000), their arm function was worse (p=0.000) and disability (DASH) was higher (p=0.000). Presence of pain (p=0.021) and worse arm function (p=0.000) were related to more disabilities on the DASH. **Discussion and conclusions:** Patients with BPI have higher prevalence of pain. Pain is related to lower general and mental health. Time after injury and severity of functional loss are predictors for pain. Pain and worse arm function are predictors for disabilities. **Clinical message:** Patients with BPI have a high risk for developing musculoskeletal pain of the non-affected arm, back and neck.

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9. Prevalence of parenthood in wheelchair-dependent persons with long-term Spinal Cord Injury in the Netherlands

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Introduction: Knowledge on prevalence and determinants of parenthood in Spinal Cord Injury (SCI) is important in the counselling of persons with SCI; however, this knowledge is scarce. Aim of this study was to estimate the prevalence of parenthood in a cohort of wheelchair-dependent persons with long-term SCI who had their injury in their reproductive years. Secondary aim was to explore demographic and injury-related determinants of parenthood after SCI. **Methods:** Multicentre cross-sectional study, part of the ALLRISC project. Information on parenthood was available in 255 persons (90%, mean age 48 years (SD 8.8)). Data on prevalence (having children before/after SCI) and determinants were obtained by questionnaires, interview and physical examination. **Results:** Overall prevalence of parenthood was 49% (50% in men, 45% in women). Of which the majority (66% in men; 72% in women) had children after their SCI. Partnership was a determinant for having children after SCI (p<0.05). Other determinants were having an incomplete lesion (men; p=0.02), normal defecation (men; p=0.01) and having a non-traumatic lesion (women; p=0.04). **Conclusions:** Prevalence of parenthood in wheelchair-dependent persons with SCI was much lower compared to that in the Dutch population (50 versus 74% in men, 45 versus 81% in women); several factors, both demographic and injury-related may contribute to this. **Clinical message:** Still half of the persons who suffered a SCI had children, and most parents had children after their injury. This information, together with information on determinants, is important in the counselling of persons with SCI who are in their reproductive years.

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11. Ventilatory support in patients with acute cervical traumatic spinal cord injury and effects on length of hospital stay and discharge destination

K.J.A.M. Bosch MD¹, C.F. van Koppenhagen MD PhD^{1,2}, H.R. Holtslag MD PhD^{1,2,3}, Prof. M.W.M. Post PhD^{1,4}

Introduction: In the acute phase, mechanical ventilation needs to be applied in many patients with traumatic cervical spinal cord injury (TSCI). **Objectives:** To study associations between ventilatory support, weaning, length of stay and discharge destination of people with recent TSCI in the acute phase. **Patients:** 153 patients with acute cervical TSCI hospitalized in the University Medical Center Utrecht between 2000-2013. **Methods:** Retrospective chart review, data extraction included patient and TSCI characteristics, application of mechanical ventilation, pulmonary complications, length of stay and discharge destination. **Results:** Of the 153 included patients, 64 were ventilated during hospitalization of which 34 (53%) were successfully weaned, 15 (23%) were still on ventilation at discharge (ranging from a few hours a day up to 24/7), while another 15 (23%) died during hospitalization. Patients on ventilation at discharge showed a longer stay on the ICU (Median 94 vs 0 days, p<0.001), longer total length of stay (Median 95 vs 21 days, p<0001), worse AIS classification (p<0.01), and slightly fewer transfers to a rehabilitation center for inpatient rehabilitation (27% versus 54%, p=0.093) compared to those independently breathing. **Conclusion:** Ventilation at discharge is associated with longer duration of hospitalization, worse AIS classification and probably less referrals for inpatient rehabilitation after acute TSCI. More research is necessary to optimise weaning, and to enhance a rapid transition from hospital to a rehabilitation facility. **Clinical message:** When a patient with TSCI is not successfully weaned, this has directly effect on the length of stay and the discharge destination.

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13. The CoMoSS program - an effective condensed client-centred modular spinal cord injury rehabilitation service

<u>H. Bouwsema PhD</u>¹, A.I.F. Spooren PhD², G.A.P.G. van Mastrigt PhD³, D.A.M.M. Vanmulken MSc, OT⁴, H.M.H. Bongers MD^4 , H.A.M. Seelen PhD⁴

Introduction: Typical rehabilitation of persons with a spinal cord injury (SCI) consists of general rehabilitation with long inpatient stay and high costs. Duration and costs may be reduced (at equal/better functional outcome) when patients are offered a condensed client-centred program. **Objective:** To evaluate and implement a condensed, modular client-centred SCI rehabilitation service (CoMoSS), consisting of: a) short clinical rehabilitation; b) early homephase; and c) client-centred modules focussing on patient's individual goals. **Patients:** Patients with a recently-acquired SCI (n=47) **Methods:** The following measures were taken at admittance, discharge, and during 3 follow-up moments (8-weeks, 6-months, and 12-months post-discharge (currently being assessed)): length-of-stay (LOS), functional status (FIM, SCIM), quality of life (QoL: SF-36, well-being, self-efficacy, satisfaction with care), and cost-effectiveness. Results were compared with a matched-control group who received standard rehabilitation. **Results:** 47 SCI-patients started the CoMoSS-program (32 male, 15 female; mean(SD) age: 58.15(16.41); AIS-A:12/AIS-B:2/AIS-

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C:8/AIS-D:25, 34% tetraplegic). Mean(SD) LOS of CoMoSS vs. controls: 137.3 (84.6) vs. 183.0 (93.4) days. The CoMoSS-group improved significantly during rehabilitation on functional status (FIM: χ^2 =28.74,p=.000, SCIM: χ^2 =28.55,p=.000), QOL (SF-36-physical-functioning: χ^2 =14.64,p=.006, SF-36-social-functioning: χ^2 =23.45,p=.000, SF-36-physical-role-functioning: χ^2 =34.63,p=.000, SF-36-pain: χ^2 =16.68,p=.002, SF-36-General-health-perception: χ^2 =14.88,p=.005). General well-being and care-satisfaction were stable over time. No significant differences were found between CoMoSS and controls, apart from higher scores for CoMoSS on SF-36-mental-health(χ^2 =14.76, χ^2 =0.000) and SF-36-vitality(χ^2 =7.03, χ^2 =0.008). Cost-effectiveness is currently assessed. Initial analyses show no significant differences between CoMoSS and controls on health-support during follow-up. **Conclusion and clinical message:** Despite a shortened LOS, CoMoSS is as effective as standard rehabilitation regarding functional status and QoL. Cost-effectiveness is currently assessed.

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15. Validation of the dutch-flemish promis fatigue item bank in patients with rheumatoid arthritis

<u>M.H.P. Crins MSc¹</u>, C.B. Terwee PhD², Prof. R. Westhovens MD PhD³, Prof. D. van Schaardenburg⁴, N. Smits⁵, J. Joly³, P. Verschueren³, K. van der Elst³, D. Cella⁶, K.F. Cook⁶, J. Dekker², M. Boers⁷, L.D. Roorda MD PhD¹

Introduction: The Patient-Reported Outcomes Measurement Information System (PROMIS) contains an item bank for measuring fatigue, which is important in the assessment of patients with rheumatoid arthritis (RA). Objective: The aim was to validate the Dutch-Flemish translation of the PROMIS Fatigue item bank (DF-PROMIS-Fatigue) in Dutch and Flemish RA patients. Patients: 1370 Dutch and 650 Flemish RA patients completed the DF-PROMIS-Fatigue (95 items). Methods: One-factor confirmatory factor analysis assessed unidimensionality. Item response theory (IRT) models evaluated the item characteristics of the item bank, to facilitate future development of a computer adaptive test (CAT). A graded item response model (GRM) was fitted and construct validity was studied. Ordinal regression models evaluated Differential Item Functioning (DIF) for e.g. language (Dutch vs. Flemish) to analyse cross-cultural validity. Results: The analyses support unidimensionality of the DF-PROMIS-Fatigue (CFI=0.996 and TLI=0.996). Only 45 out of 4465 (1%) item pairs were marked as possibly locally dependent. The data of the item bank fit the GRM, and showed good coverage across the fatigue continuum (threshold-parameters: -3.8 to 5.8). The item bank showed good crosscultural validity: none of the DF-PROMIS-Fatigue items showed DIF between Dutch and Flemish language. Analyses of construct validity are in progress and will be presented at the conference. Discussion: The results indicate that the items of the DF-PROMIS-Fatique fit a GRM and demonstrate good coverage across the range of the fatique domain. Clinical message: The DF-PROMIS-Fatigue can be used to develop a CAT for measuring fatigue in Dutch and Flemish RA patients.

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19. The squat test is a feasible and valid test to assess muscle endurance in children with CP

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Introduction: Clinical decision making for children with cerebral palsy (CP) with mobility problems requires valid assessment of their ability to repetitively generate forces, here muscle endurance. Unfortunately, a generally accepted and validated clinical test is not available. Objective: We aimed to determine whether a squat test is suitable to measure muscle endurance by evaluating test performance, muscle fatigue and execution in children with CP and typically developing (TD) peers. Patients: Twenty children with bilateral spastic CP (6-19years; GMFCSI/II/III: N=5/13/2) and sixteen TD peers (7-16years). Methods: Test performance was measured as the number of two-legged squats until fatique (max20). Muscle fatique was assessed from changes in electromyography (EMG). Joint range-of-motions (ROM) and net torques were calculated at the beginning and end of the test. Results: Test performance differed between CP and TD children. Seventeen CP children performed less than 20 squats (median=13;IQR=7-19), while all TD children performed the maximum of 20. EMG median frequency decreased and EMG amplitude increased in quadriceps of both groups, indicating presence of muscle fatigue. No differences were observed between the beginning and end, except for knee ROM which increased in TD and decreased in CP. Discussion and Conclusions: Squat test performance was reduced in children with CP compared to TD. Quadriceps muscle fatigue in both groups confirms that the squat test assesses muscle endurance. Minor differences in execution indicate the importance to closely monitor test execution. Clinical Message: The squat test is a clinically feasible and valid assessment of muscle endurance in children with CP.

Picture 1: https://admin.eventure-online.com/parthen-uploads/89/6DCRM/img1 295496 euJra43ygy.jpg
Caption 1: Fig1. Stick figures showing a typical squat execution of a TD child and child with CP.

Picture 2: https://admin.eventure-online.com/parthen-uploads/89/6DCRM/imq2_295496_euJra43yqy.jpg

Caption 2: Fig2. Maximal number of squats by CP children (N=20; GMFCS: I=black, N=5; II=dark grey, N=13; III=light grey, N=2). All TD (N=16) performed 20 squats.

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23. Anxiety affects Disability and Quality of Life in patients with Painful Diabetic Neuropathy

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Introduction: Painful Diabetic Neuropathy (PDN) is known to negatively affect psychosocial functioning as expressed by enhanced levels of anxiety and depression. **Objective:** To specify diabetes and pain related fears, hereby identifying potential targets for intervention. **Patients:** This questionnaire-based cross-sectional study included 154 patients with PDN (mean age 65.7±6.6 years). **Methods:** Linear regression analyses corrected for age, gender, pain intensity, pain duration and insulin treatment were performed to assess the associations of various fear questionnaires [Hypoglycaemia Fear Survey (HFS), Tampa Scale of Kinesiophobia (TSK), Pain Anxiety Symptom Scale (PASS-20), Falls

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Efficacy Scale-I (FES-I), Tampa Scale of Fatigue (TSF), Brief Fear of Negative Evaluation Scale (BFNE)] with quality of life (QoL)(Norfolk Quality of Life Questionnaire, Diabetic Neuropathy Version, QOL-DN) and disability (Pain Disability Index, PDI), respectively. **Results:** All fears were independently associated with QoL and disability (p<0.001 for all variables). Stepwise backward regression models including all fear questionnaires showed that pain intensity, fear of fatigue, fear of hypoglycaemia and fear of falling were significantly associated with decreased QoL; β =0.253;p<0.001; β =0.134;p=0.045; β =0.216;p=0.003, and β =0.385; p<0.001, respectively; R2=0.629. Pain intensity and fear of falling were significantly associated with disability; β =0.283;p<0.001 and β =0.540;p<0.001 respectively; R^2 =0.544. **Conclusion:** In patients with PDN, pain intensity, fear of falling were associated with disability. **Clinical message:** Unraveling specific fears enables us to identify targets for behavioral interventions that aim to improve psychosocial well-being in patients with PDN.

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25. Psychometric properties of the SAQOL-39NL in a stroke population

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Introduction: Instruments to evaluate HRQL are often unsuitable for stroke patients with aphasia. Recently, a Dutch version of the Stroke and Aphasia Quality Of Life-scale (SAQOL-39NL) was developed (3 domains: physical, psychosocial and communication; 39 items; answering categories 0-5). It's psychometric properties have only been partially assessed. Objective: To evaluate the psychometric properties of the SAQOL-39NL in stroke patients. Patients: Stroke patients with (n=59) or without (n=81) aphasia treated in Rijndam Rehabilitation, the Rijnlands Rehabilitation Center, or Sophia Rehabilitation, who were included in either the TEA-study or the SCORE-study. Methods: The SAQOL-39NL and EQ5D were administered 3 months after start of rehabilitation. Acceptability was explored by assessing floor and ceiling effects and percentage of missing items. For internal consistency, Cronbach's alpha was calculated. For construct validity, the intercorrelations between domains and total scores, and the association with the EQ5D were assessed using Pearson's r. Results: The mean age of the patients was 60.4 years (SD 11.1), 62% were male. Mean total SAQOL-39NL score was 3.93 (SD 0.68). No missing data, floor or ceiling effects were found. Internal consistency was excellent (Cronbach's alpha = 0.96). Intercorrelations between domains and total scale were good to excellent (r=0.54 to 0.88). The association with the EQ5D was moderate (r=0.54). **Discussion and conclusions:** The SAOOL-39NL is an acceptable, valid, and reliable instrument to evaluate the HROL in stroke patients. It's responsiveness after stroke needs to be determined. Clinical message: The SAQOL-39NL is useful for assessing HRQOL in clinical practice and research.

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27. Implementation of a new rehabilitation treatment for multi-trauma patients: traumarehabilitation in the fast lane

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Introduction: In Netwerk Acute Zorg Limburg multi-trauma patients are transferred from hospital to a specialised rehabilitation department at an earlier stage than conventionally, allowing intensive rehabilitation training to start sooner. This Supported Fast Track Trauma Rehabilitation Service (SFTRS) features integrated collaboration between the trauma surgeon and the rehabilitation physician in both hospital and rehabilitation centre (RC). Objective: Implementation of SFTRS in two additional Dutch trauma regions (Acute Zorgregio Oost and TraumaNet AMC). Patients: Multi-trauma patients admitted to the hospital. Methods: Implementation plan according to the Grol & Wensing model (2006) using indicators set for structure (screening instrument for multi-trauma patients, timeliness), process (implementation plan procedure followed) and results (EQ-6D, patient satisfaction). Results: The implementation was largely successful, i.e. the SFTRS characteristics were replicated, screening instrument was used in both centres and the necessary activities were performed on schedule, although the lack of a fixed consultation schedule and the relatively small number of patients meant that it took longer to establish routines. The enabling factors were good support from management, temporary financing from Stichting Kwaliteitsgelden Medisch Specialisten and a workshop. Patient satisfaction: 83% (hospital) and 100% (RC). Discussion/conclusions: The SFTRS concept has proven to be successfully implementable in additional trauma centres using a well-described implementation plan. It is expected that this can also be done in other trauma care chains. Clinical message: A detailed implementation plan for SFTRS was tested and is now available to be used in other Dutch regions for improving medical specialist care for multi-trauma patients.

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29. Hemiparetic gait during Lokomat walking: an evaluation of muscle activity

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Introduction: As a result of stroke, patients often show impaired walking ability. The Lokomat (Hocoma AG, Volketswil, Switzerland) is an actuated exoskeleton that can be used for gait rehabilitation by providing robotic guidance during gait. For the design of training protocols it is crucial to understand the neuromuscular control of Lokomat guided gait. **Objective:** To determine differences in gait related muscle activity between treadmill and Lokomat walking, and to evaluate the effects of guidance, in both stroke patients and healthy walkers. **Patients:** Ten stroke patients with unilateral paresis (eight females, 64.4±6.3 years, >3 months post stroke, FAC 2-4) and ten healthy controls (seven females, 62.7±4.8 years). **Method:** Participants walked on the treadmill and in the Lokomat (guidance forces 50% and 100%, speeds 1.0 and 2.0 km/h). Electromyography was recorded bilaterally from Gluteus Medius (GM), Biceps Femoris (BF), Vastus Lateralis (VL), Gastrocnemius Medialis (MG), and Tibialis Anterior (TA). **Results and discussion:** In the Lokomat stroke patients showed muscle activity that was more symmetrical and similar to healthy walkers, mainly in muscles responsible for weight bearing and propulsion. However, this seems to be associated with the lowered muscle amplitude in both groups, when compared to treadmill walking. Muscle activity was not affected by guidance level, but muscle amplitude was increased with increasing speed. **Conclusion and clinical message:** Walking in the Lokomat seems to assist weight bearing and propulsion in stroke patients, but this is accompanied by a reduction in the active contribution. Active contribution can be encouraged by training at higher speeds.

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31. Is a caregiver available and suitable to help?

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Introduction: In the ongoing Care4Stroke study we evaluate the effects of a caregiver-mediated exercises (CME) program combined with e-health services after stroke, aimed at early supported discharge (ESD). This intervention can only be executed if a caregiver is available and suitable for applying these services. **Objective**: To describe how many eligible patients from Reade (rehabilitation centre in Amsterdam), were excluded from the Care4Stroke study as a result of lacking an available and/or suitable caregiver and to describe the reasons for exclusion. **Patients and methods**: All patients admitted to the neurorehabilitation wards were screened for eligibility between April 2014 and February 2016 and reasons for exclusion were recorded, when concerning the caregiver they were further explicated. **Results**: A total of 508 patients were screened, of which 463 patients were excluded. A total of 80 patients (17%) did meet all the inclusion criteria, but were excluded because they did not want to ask a caregiver (12 patients), had no caregiver available (25 patients) or had no suitable caregiver (43 patients). **Discussion and Conclusion**: 17% of screened patients were not able or willing to assign a caregiver to support them during CME. It is needed to further explore possible cross-cultural differences. **Clinical message**: Assistance of a caregiver is increasingly emphasized in healthcare policy, for example to allow ESD. The present results show that a group of patients fail by not having an available and/or suitable caregiver to support them in CME. This is important information for physicians and policy makers.

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Plenary poster presentations 2

Friday 11 November, 12.10 - 12.30

Chair: Hans Bussmann PhD

2. Pharmacologic interventions for treating acute phantom limb pain in patients with lower limb amputation (LLA); a systematic review

J.M.A. Karstenberg-Kramer MSc¹, E.C.T. Baars MD¹, R.W. Winter MD¹, S.M. Brink MSc¹, Prof. J.H.B. Geertzen MD PhD²

Objective: The aim of the review is to summarize the evidence of effectiveness of pharmacologic interventions in treating acute phantom limb pain (phantom limb pain developed within 6 months after amputation) in LLA patients. **Search strategy:** Electronic database search: Web of Science, PsychINFO, Cochrane Library, Embase and Pubmed were searched up to July 2015 for trials studying pharmacologic treatment for treating acute lower limb phantom limb pain. **Selection of articles:** We included studies with: 1. sample sizes of 5 or more; 2. studying the effectiveness of pharmacologic interventions in LLA patients and acute phantom limb pain; 3. the outcome assessed was change in pain intensity measured by any standard scale. **Evaluation of articles and results:** Two assessors independently reviewed the titles and abstracts of all articles identified. Full text of relevant titles and abstracts were retrieved. The search identified 1891 titles and abstracts. After removal of duplicates 994 titles and abstracts remained. 951 titles and abstracts were excluded. 43 papers were retrieved full text but did not match inclusion criteria. **Conclusion:** We found no evidence of pharmacologic interventions in treating acute phantom limb pain in LLA patients. There is a need for studies assessing pharmacologic interventions in acute phantom pain useful for clinical practice.

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4. Requirements on an intervention for stimulating physical activity in physically disabled people: a focus group study amongst experts

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Introduction: In the Netherlands physically disabled people participate less in physical activity compared with healthy people. Existing interventions stimulating physical activity are limited since they generally reach their target population through intermediate organizations. **Objective:** To determine requirements that experts, working in the field of adapted physical activity, pose on an intervention stimulating physical activity for physically disabled people. **Patients:** Experts, working in the field of adapted physical activity. **Methods:** Focus groups were held with experts (n=28) working in the field of adapted physical activity. Audio-recordings were analysed using thematic analysis. Relationships between the emerged codes were established and inserted in an integrated model of Physical Activity for people with a Disability and the Intervention Mapping model. **Results:** Experts express no need for a new intervention. Collaboration between different organisations should be improved. An intervention should focus on changing attitude towards physical activity of both the individual and environment. This change would increase intrinsic motivation and risk awareness of the individual, and social support of the environment. An intervention should include individual

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coaching, feedback, a trial period, role models and an appropriate marketing strategy. Suggestions for approaching the target population, and finance and responsibility for an intervention are provided. **Discussion and conclusions:** There is no need for a new intervention, existing interventions should be adapted. Experts expressed a need for increased collaboration between organisations. **Clinical message:** Physical activity in physically disabled people should be stimulated using an existing intervention which should be adapted to fulfil the requirements as posed by experts.

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6. Effect of variable practice on the motor learning process in manual wheelchair propulsion

M.T. Leving MSc¹, R.J.K. Vegter PhD², S. de Groot PhD³, Prof. L.H.V. van der Woude PhD²

Introduction: Handrim wheelchair propulsion is a skill that needs to be learned during rehabilitation. It has been suggested that a higher movement variability benefits the motor learning process of wheelchair propulsion. Objective: To determine the effect of variable practice on the motor learning process of wheelchair propulsion in novice ablebodied participants. Motor learning was operationalized as improvements in mechanical efficiency and propulsion technique. Participants and Methods: 11 Participants performed a pre-test, 7 practice sessions and a post-test. During the practice sessions, participants performed one-hour of variable practice, consisting of five wheelchair-skill tests and a 30 min wheelchair basketball game. Pre- and post-test were performed in a wheelchair on a motor-driven treadmill (1.11 m/s) at a relative power output of 0.23 W/kg. Energy consumption and the propulsion technique variables were calculated. Results: Comparison of the pre- and the post-test showed that variable practice resulted in a 27% relative increase in mechanical efficiency. With regard to propulsion technique, the push frequency and the braking torque at (de)coupling reduced and the contact angle of the hand with the handrim increased. Discussion and Conclusion: The study showed that variable practice results in an increase in mechanical efficiency and an improvement in propulsion technique. Interestingly the large relative improvement in mechanical efficiency was concomitant with only moderate improvements in the propulsion technique, suggesting that other factors besides propulsion technique contributed to the higher efficiency. Clinical message: Variable training proposed here is an effective way to improve mechanical efficiency and wheelchair propulsion technique in novice users.

Picture 1: https://admin.eventure-online.com/parthen-uploads/89/6DCRM/imq1 295745 w050rh4b10.png

Caption 1: The experimental protocol. Participants received the pre-test, 7 variable practice sessions and the post-test.

Picture 2: https://admin.eventure-online.com/parthen-uploads/89/6DCRM/img2 295745 w050rh4b10.png

Caption 2: Change in mechanical efficiency between the pre- and post-test (N=11). Significant (p<0.05) effect of time is marked(*).

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8. Effectiveness of amantadine on behavioral problems due to acquired brain injury: A systematic review

<u>A.P.M. Backx MD</u>¹, A.J.W. ter Mors MD², P. Spauwen PhD², R. Ponds PhD^{1,3}, Prof. P.N. van Harten PhD³, Prof. C.M. van Heugten PhD^{3,4}

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Objective: To systematically review the literature on the effectiveness of amantadine on reduction of behavioural problems (aggression/agitation, apathy, dysexecutive syndrome), increased participation and increased quality-of-life (QoL), in patients suffering from acquired-brain-injury. Search: Systematic search in PubMed/EMBASE/CINAHL (last search 8-4-2016), keywords: brain injury, prefrontal cortex, neurobehavioral manifestations, amantadine, participation, behavioral disorders, quality-of-life. Selection: Dataselection and extraction is currently being done by two independent reviewers. Inclusion: adults with acquired-brain-injury, use of quantitative outcome measurements on behavior/participation/QoL. Exclusion: neurodegenerative diseases, disorders of consciousness. Quality of included studies is assessed using CONSORT and CASP criteria. Evaluation and preliminary results: Data synthesis is currently ongoing. Of 630 records identified, 26 were assessed full-text. Nine articles were selected (3 case-reports/series, one prospective cohort study, one retrospective study, one single case experimental design, 3 randomized controlled trials). The two high quality randomized controlled trials (RCT) are inconclusive about the effect of amantadine on irritability, one showing positive and one showing no effect. One RCT measuring executive functioning and agitation without effect of amantadine was of low quality. A prospective cohort study of moderate quality showed a positive effect on executive functioning. Five other non-randomized studies measuring effect of amantadine on behaviour were of poor quality (positive effect in all 4 studies measuring aggression/agitation, positive effect in both studies measuring apathy, positive effect in all 3 studies measuring executive functioning). QoL and societal participation were not measured in these studies. Amantadine was well-tolerated. Tentative conclusion: Literature is of low quality and inconclusive. More high quality research is required.

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10. Effects of exercise on gastrointestinal function in people with long-term spinal cord injury: a randomized-controlled trial

N. van Munster MSc¹, S. de Groot PhD^{2,3}, A.J.T. Bakkum PhD⁴, C.A. Smit MD¹, T.W.J. Janssen PhD^{2,4}

Introduction: People with spinal cord injury (SCI) often have gastrointestinal problems. Since positive effects of exercise on chronic constipation has been shown in the able-bodied population, similar effects might be expected in people with SCI. **Objective:** To examine the effect of a 16-weeks exercise programme, using either a handcycle (HC) or hybrid cycle (HYB; handcycling with electrical stimulation-induced leg cycling) on gastrointestinal function in people with long-term SCI. *Participants*: 19 individuals with SCI (time since injury ≥ 8 yrs, age 30-64yr) were randomly assigned to a HC (N=9) or HYB (N=10) group. **Design:** Multicentre randomized-controlled trial. HC and HYB trained twice a week for 16 weeks at a moderate intensity. Gastrointestinal function was evaluated with the Neurogenic Bowel Dysfunction Score (NBD), measured at baseline (T1), after 8 (T2) and 16 weeks (T3) of training and 26 weeks after the training program (T4). **Results:** NBD sum score at baseline was not significantly (p=0.108) different between HC (9.7±4.8) and HB (14.7±8.0). No significant change over time for the total group (T1: 12.7±6.8, T2: 12.4±5.6, T3: 11.3±6.4 and T4: 13.2±6.5) (p=0.33) or between the groups over time (p=0.85) was found. **Discussion and conclusions:** Sixteen weeks hybrid or handcycle exercise does not seem to improve the NBD score in people with SCI. The training programme might have been too short or the intensity too low to gain significant results. **Clinical message:** Sixteen weeks, 2x/week, moderate intensity hybrid or handcycle exercise does not seem to have benefits on gastrointestinal problems for people with long-term SCI.

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12. Unpacking community mobility: a qualitative study into the embodied experiences of stroke survivors

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Introduction: Many stroke survivors experience mobility problems. Mobility is described as complex and dynamic and therefore a better theoretical understanding is needed. Objective: To enrich the discussion on mobility in stroke rehabilitation by translating the theoretical repertoires of mobility from the context of geography to rehabilitation. Patients: 33 stroke survivors with moderate to severe stroke who had received multidisciplinary treatment in a dutch rehabilitation stroke unit. Methods: A qualitative research methodology was applied, including in-depth interviews with stroke survivors. Results: This study revealed social and material differences in clinical, private and public places; ambivalences and shifting tensions in bodily, family and community life and differences in access to resources to be used for mobility. Moving around was not a matter of being physically able to walk independently; it also involved dealing with different human and non-human actors. Stroke survivors did a lot of tinkering to balance exercise and training, family and working life, leisure and pleasure, and had to renegotiate their mobility in each context. Discussion and conclusions: Mobility has many aspects that interact with each other in multiple ways for stroke survivors after discharge. The current focus on adherence to mobility and exercise training at home needs to be critically reviewed as it does not capture the multiplicities embodied in real-life settings. Clinical message: After discharge, sustaining or improving physical activity and community ambulation of stroke survivors should be trained at home and in the community, in order to deal with the complexities in home and community life.

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14. Associations between time since injury and participation measured by the USER-P in Dutch people with long-term spinal cord injury

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Introduction: With participation as an important outcome measure in rehabilitation and longer life expectancy in persons with spinal cord injury (SCI) it is important to investigate participation in persons with long-term SCI. Objective: To describe relationships between time since injury (TSI) and participation in persons with tetraplegia and paraplegia. Patients: 265 wheelchair-dependent persons aged 28-65 years, with SCI for ≥10 years and age at injury between 18-35 years. Methods: Multicentre cross-sectional study in three TSI strata: 10-19, 20-29 and ≥30 years post injury. The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) consists of 3 scales: Frequency (including subscales for Productive, Leisure, and Social activities), Restrictions and Satisfaction. Linear regression analyses were used, for tetraplegia and paraplegia separately, to study the effect of TSI on participation and correct for possible confounders. Results: In persons with tetraplegia (N=107), longer TSI was significantly associated with reduced Leisure activities (p=0.004). There was a trend towards lower scores on the Frequency-scale (p=0.057) and Productive activities subscale (p=0.054) with longer TSI. In persons with paraplegia (N=158), longer TSI was associated with reduced Productive activities (p=0.039). TSI was not associated with participation Restrictions and Satisfaction with participation. Conclusion: After correction for confounders, longer TSI is associated with a reduced Frequency of participation in persons with long-term SCI. Interestingly, this negative change is not accompanied by a similar change in the person's experience of participation. Clinical Message: Rehabilitation physicians must be aware of participation problems in persons with long-term SCI.

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16. Implementation and process evaluation of the Energetic study

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Energetic is a self-management outpatient rehabilitation intervention for patients with a neuromuscular disease aimed at improving social participation, physical endurance and alleviating chronic fatigue. Energetic covered four months and included four modules: 1)individually tailored aerobic exercise training; 2) education about aerobic exercise; 3) self-management training in applying energy-conservation strategies; and 4) implementation and relapse prevention in daily life. Recently, a randomised controlled trial (RCT) showed the effectiveness of *Energetic*. To conduct this RCT, the programme was implemented in three different healthcare settings in the Netherlands: an outpatient rehabilitation department of a university medical centre, a regional rehabilitation centre and a community health centre. A qualitative research was carried out to evaluate the implementation of the programme in these settings from both patients' and professionals' perspectives. In the first group patients and their next of kin were approached for an individual semi- structured interview, the second group patients participated in a focus group to evaluate facilitators and barriers related to the programme, trainers and organisation. In addition, semi-structured interviews were performed with all stakeholders concerning the recruitment, logistics and content of the intervention. Protocol adherence by trainers was monitored by using a logbook, intervision and by process evaluation for the trainers. The process evaluation showed positive results in the three settings regarding the results, the trainers and the organisation. We will also present the different facilitators and barriers that were identified regarding the content of the programme and logistics. This process evaluation will help future implementation in different settings and dissemination.

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18. Participation and quality of life in children with Spinal Muscular Atrophy

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Introduction: Spinal Muscular Atrophy (SMA) is a progressive motor neuron disease causing muscle weakness leading to disability. Since there is no curative treatment available, rehabilitation care to support participation in society is the only treatment available. **Objective:** To describe the level of participation and quality of life in children with SMA, in order to optimize rehabilitation care for these patients. **Patients:** 73 children with SMA type 2 and 3 were approached. Children with SMA type 1 were excluded because of their short life expectancy. **Methods:** Questionnaires on participation (Life-H), quality of life (Kidscreen) and a set of determinants were answered by patients and parents. Descriptive statistics were performed. **Preliminary results:** 47 patients participated in the study. Mean age of children was 9 years (SD 4.9), 57% were male. SMA subtype 2 and 3 was diagnosed in 38 respectively 9 children. 7 children were preschool aged, 22 in primary school, 16 in secondary school (7 respectively 3 special education), 1 followed home education and 1 was not attending school at all. Children experienced their overall quality of life comparable to European norm data. The subdomain 'physical wellbeing' was rated lower. More detailed results (including results on participation) will be presented at the conference. **Discussion and conclusions:** Children with SMA report a similar overall quality of life to healthy children, but physical wellbeing is rated lower. **Clinical message:** Better knowledge of participation and quality of life in children with SMA will help to improve rehabilitation guidelines for children with SMA.

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20. Long-term outcomes of multidisciplinary rehabilitation for chronic musculoskeletal pain. Follow-up chronic musculoskeletal pain rehabilitation

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Objectives: Evidence for the effectiveness of multidisciplinary rehabilitation for chronic musculoskeletal pain (CMP) on the longer term is scarce. The aim of the present study was to describe the two-year outcomes of a 15-week multidisciplinary pain rehabilitation programme in patients with mixed CMP. **Methods:** Data were recorded routinely at admission, discharge, and at3, 12 and 24 months' follow-up. Assessments included the Pain Disability Index, the Pain Catastrophizing Scale, the Multidimensional Pain Inventory, numerical scales for pain and fatigue, the RAND-36-Item Health Survey and questions on healthcare usage and work status. **Results:** A total of 165 patients were included initially, with data from 125 (76%) and 120 (73%) patients being available at 12 and 24 months' follow up, respectively. There were statistically significant improvements for all clinical outcome measures between admission and discharge, and at 3, 12 and 24 months' follow-up. At 24 months, the number of healthcare providers visited in the previous year had decreased significantly and within the group of patients working at admission (50%), the proportion of those working 25 hours or more per week had increased significantly from 16% to 48%. **Discussion and conclusions:** After multidisciplinary treatment for CMP improvements in pain and functioning are maintained over 2 years, whereas health care usage decreased and the number of working hours among working patients increased. **Clinical message:** Even two years later benefits of a 15-week multidisciplinary pain rehabilitation programme in patients with mixed CMP were still present with a sustained effect on health care use and employment.

Picture 1: https://admin.eventure-online.com/parthen-uploads/89/6DCRM/img2 292091 dl5cU1eGW5.png

Caption 1: Estimated mean admission and follow-up scores of quality of life

Picture 2: https://admin.eventure-online.com/parthen-uploads/89/6DCRM/img1 292091 dl5cU1eGW5.png

Caption 2: Estimated mean admission and follow-up numerical rating scale scores for pain and fatigue in patients with chronic musculoskeletal pain

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22. No gain from multidisciplinary rehabilitation treatment for spouses of patients with non-specific chronic pain

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Introduction: Research has given insight in the influence of the spouse on the complaints of the patient with non-specific chronic pain and vice versa. The effect of multidisciplinary rehabilitation treatment (MRT) on the spouse of the patient has not been studied yet. **Objective:** To investigate whether MRT of patients with non-specific chronic pain also affects their spouses. **Patients:** Patients with chronic pain, admitted to an outpatient rehabilitation treatment, and their spouses. **Method:** Prospective cohort study. Participants fill out questionnaires at: T1 pre-treatment, T2 start of

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treatment, T3 end of treatment, T4 three months after treatment. Primary outcome measure: psychological distress of the partners (Symptom Checklist-90, SCL-90, range 90-450). Secondary outcome measures: life satisfaction (RAND-36, range 0-100) and strain of spouse (Caregiver Strain Index, CSI, range 0-13). **Results:** Eventually 39 couples were included for analysis. Scores for the T1, T2, T3 and T4 of the patient were for the SCL-90 146(42), 152(48), 132(39), 126(42), respectively, this is a statistically significant change. For the spouses the scores were 112(21), 119(27), 114(33) and 106(18) respectively, NS. The scores of the social-domain of the RAND-36 changed statistically significant for the spouse, they were however not clinically relevant: 87(15.7), 86(16.2), 91(15.4) and 95(10.1). No difference were found in the scores of the spouses on the CSI or other domains of the RAND-36. **Discussion and conclusions:** Our study confirms that patients with non-specific chronic pain benefit from the MRT. However, for the spouses, no clinically relevant change was detected.

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24. Lisfranc and Chopart amputation: a systematic review

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Objective: Lisfranc and Chopart amputation are historically controversial procedures. To obtain evidence for the pro's and con's we performed a systematic review to analyze wound healing, need of re-amputation at a higher level, and ambulation after a Lisfranc or Chopart amputation. Search strategy: Literature search was performed in five databases (Cochrane, Embase, Medline, PsyInfo, and Pedro), using database specific search strategies. Reference lists were studied to include relevant studies that were missed in the search. **Selection of articles:** 1879 publications were found. Excluded publications concerned editorials, reviews, letter to the editor, no full text available, case reports, not meeting the topic, and written in an language other than English, German, or Dutch. After selection, 10 publications were included in this review. Evaluation of articles and results: Preliminary analyses showed that Lisfranc amputations have the best wound healing rates, with 21% failure of wound healing, compared to 25% failure after modified-Chopart, and 61% failure after conventional Chopart amputation. The majority of wound healing problems were seen in patients with diabetes, including amongst others ulceration, infection and ischemia. Patients after Lisfranc, modified, and conventional Chopart amputation were able to ambulate for short distances without prosthesis. Lisfranc amputation resulted in higher level of ambulation. Conclusion: Preliminary analyses suggest that Lisfranc and modified-Chopart amputations may offer a good alternative to Pirogoff, Syme, transtibial, and conventional Chopart amputations. Both amputations offer good wound healing rates and short distance ambulation without the need to wear prosthesis.

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28. Adherence and satisfaction with a web-based brain training program in chronic stroke patients

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Background: Despite increased use of computer-based cognitive rehabilitation (CBCR) programs for stroke patients, little is known about adherence and patient satisfaction. **Objective:** To explore stroke patients' adherence and satisfaction with a CBCR program. **Methods:** This study was part of a randomised controlled trial comparing a CBCR

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program (intervention) with electronic information about the brain (control) in stroke patients. Patients in the control group were offered the program after termination of the trial at 16 weeks. The program consisted of a home-based brain gaming during 8 weeks, 5 days a week, with an advised playtime of 600 minutes. Adherence data were extracted from the CBCR-software. Satisfaction was measured in the control group only, using a self-developed questionnaire (unsatisfied/ neutral / satisfied). **Results:** 105 patients (53 intervention/ 52 control) were included, median age 58 (range 56-74) years, with 66 men (63%). 84/105 (80%) patients completed ≥1 training session with a median playtime of 424 minutes. 25/84 (30%) patients completed the requested 600 minutes. 38/52 (73%) patients completed the satisfaction questionnaire and 34 of the 38 patients (90%) were satisfied with the training. **Discussion and conclusions**. 80% of stroke patients used the 8-week CBCR program at least once, with median playtime among users being 424 minutes. 90% of the patients was satisfied with the training. CLINICAL MESSAGE. Although once offered the majority of stroke patients uses a CBCR program and is satisfied, the actual playtime is relatively low, warranting the need for tailored adjustments increasing adherence.

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30. One, two, three, towards self-responsibility?! Exploring intentions for self-management of parents of children with a chronic condition and rehabilitation professionals

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Introduction: Within Dutch pediatric rehabilitation services self-management increasingly is acknowledged as critical basis of successful interventions, characterized by substantial responsibility, active participation and partnership with professionals. For many parents and their children indeed self-management is applicable, but there are others for whom it is a problem. Professionals differ in their opinions about parent involvement. Better comprehension of intentions of parents and professionals is needed to accommodate and achieve more optimal self-management. **Objective:** This study aims to explore intentions and motivations for self-management of parents and professionals. Sample: 143 parents and 104 professionals. Methods: In a survey motivation, attitudes and competency for selfmanagement were measured among parents and professionals within 5 rehabilitation teams. Results: Analysis indicated 71% of the parents perform self-management, although 43% have difficulties to sustain this under stress. 29% of the parents believe self-management is important, without being active themselves. Parents and professionals have both intrinsic-, but also considerable extrinsic motivations for self-management. Most professionals believe parents should be active team members, but they have different opinions about how active this should be. Intrinsic motivation was significantly correlated with higher competency for self-management (r=.53). Conclusion and discussion: There is no optimal match between intentions of parents and professionals with regard to selfmanagement. Further research on the underlying perceptions of parents and professionals about self-management as well as perceived barriers and facilitators is recommended. Clinical message: This study creates opportunity for professionals to reflect on their own and parent's orientations, which might help to optimize their self-management supportive behavior.

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