THE LATE EFFECTS OF POLIO Current Research in Post-Polio Syndrome

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May 15, 2011

Orange County Post Polio Support Group

News This Year Kind of Medium Rare

- There is 1 active study of post polio listed in ClinicalTrials.gov. The study looking at brain fatigue has been completed.
- There was no new post-polio research presented at the American Academy of Neurology meeting in Hawaii last month.
- But many post polio researchers around the world continue to enlarge our knowledge.

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Clinical Trials

- Study of Mental Fatigue in Polio Survivors
- This study is currently recruiting participants.
- Verified by Uniformed Services University of the Health Sciences, March 2007
- First Received: June 14, 2007 Last Updated: June 15, 2007
- Sponsored by: Uniformed Services University of the Health Sciences Information provided by: Uniformed Services University of the Health Sciences
- ClinicalTrials.gov Identifier: NCT00487487
- **Post-Poliomyelitis** Syndrome (PPS) is the term describing the new problems affecting **polio** survivors many years after recovery from paralytic **polio**.
- Among the symptoms, fatigue is one of the most frequent and debilitating. In addition to physical incapacitation, the fatigue of PPS also affects mental function. The term "brain fatigue" is usually used by patients to express problems on the areas of attention, concentration, memory and clear thinking.
- Unfortunately, little is known about cognitive fatigue of PPS patients. This study is meant to examine if mental
 impairment is present in PPS patients and, if so, how it interferes on the self-function of patients. Patients will
 undergo an interview, clinical and neurological evaluation, and a battery of screening laboratory tests to make sure
 they are eligible for the study. Patients who qualify will undergo neuropsychometric tests in order to assay
 performance in the main areas of cognitive functioning. Through this organized approach we expect to be able to
 determine if mental fatigue is a significant problem affecting polio survivors, what areas are most affected, and
 how it may interfere with daily living.

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Probably Not the Same Study But Goals the Same

- J Rehabil Med. 2011 Jan;43(1):39-45. ٠
- Post polio syndrome: fatigued patients a specific subgroup?
- Östlund G, Wahlin Å, Sunnerhagen KS, Borg K.
- Source
- Divison of Rehabilitation Medicine, Department of Clinical Sciences, Danderyd Hospital, Karolinska Institutet, Stockholm, Sweden. Gunilla.Ostlund@ki.se
- Abstract
- **OBJECTIVES:**
- To examine the characteristics of fatigued and non-fatigued post-polio patients and to define potential subgroups across the fatigue continuum.
- **DESIGN:**
- Multi-centre study.
- SUBJECTS:
- A total of 143 post-polio patients were subdivided on the basis of percentile distribution into a fatigue group, a intermediate group, and a non-fatigue group, using the Multi Fatigue Inventory 20 general fatigue ratings. ٠
- METHODS:
- Data on background, quality of life, fatigue and pain were collected. Descriptive statistics and correlations in each group and analysis of variance and χ^2 for group comparisons were performed. Non-linear regressions were employed to evaluate differences in the strength of associations between physical and mental fatigue, on the one hand, and vitality on the other.
- **RESULTS:** .
- The fatigued group was younger, had shorter polio duration, more pain, higher body mass index, lower quality of life and was more physically and mentally fatigued. A higher proportion of this group had contracted polio after 1956 and was under 65 years of age. Mental fatigue had a relatively higher explanatory value than physical fatique for differences in vitality in the fatiqued group, whereas reversed patterns were seen in the other groups.
- CONCLUSION: May_15, 2011
- 715, 2011 Orange County Post Polio Fatigued post-polio patients can be considered as a subgroup

The Current Active Study

- Arm Cycling to Improve Fitness in Polio Survivors
- This study is currently recruiting participants.
- Verified on January 2011 by Royal College of Surgeons, Ireland
- First Received on December 10, 2010. Last Updated on January 5, 2011
- **Sponsor:** Royal College of Surgeons, Ireland
- Collaborators: Post Polio Support Group Ireland, Beaumont Hospital ClinicalTrials.gov Identifier: NCT01271530

Purpose

- The aim of this study is to investigate the effect of upper limb cardiovascular training on fitness, energy cost of walking, fatigue and pain in polio survivors. Polio survivors often have difficulty accessing aerobic forms of exercise due to limitations in mobility, pain associated with walking and fatigue. This can result in becoming physically unfit and places polio survivors at risk of secondary heath problems due to inactivity. A large percentage of polio survivors have lower limb involvement but have strong arms. The participants in this study will exercise at home using simple arm cycles for 8 weeks. They will attend for assessment on two occasions. All exercise will be prescribed by a Physiotherapist and includes measures to ensure safety while exercising at home.
- •
- Primary Outcome Measures:
- Six Minute Arm Test [Time Frame: Eight weeks]
- The Six Minute Arm test is a submaximal cardiovascular fitness test. The American College of Sports Medicine recommend submaximal fitness testing, limited to 6-12
 minutes and using either four limb ergometry or an upper limb ergometer in prior polio patients. The 6 Minute Arm Test (Hol et al 2007) is such a submaximal upper limb
 exercise test, which has been developed and found valid and reliable in spinal cord injury.
- The Physical Activity Scale for Persons with Physical Disabilities [Time Frame: Eight weeks]
- The Physical Activity Scale for Persons with Physical Disabilities is a subjectively reported survey of activity levels in people with physical disabilities. Preliminary validation has been completed by Washburn et al (2002).
- Secondary Outcome Measures:
- May Upper Line Maximal Voluntary Isometric Contraction Body Mass Index and Waist to hip Ratio Hand Grip Motor Fatigue Short Form 36 Version 2 (SF-36 v2)

Ongoing Initiatives

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Global Polio Eradication Initiative as of May 2011 http://www.polioeradication.org/Dataandmonitoring/Poliothisweek.aspx

- Despite the recent progress seen in Afghanistan, India and Nigeria, there is only one less case worldwide than was seen at this time last year. Similarly, there are now only six fewer infected districts globally than there was at this time last year.
- Pakistan, the Democratic Republic of the Congo (DR Congo) and Chad account for the overwhelming majority of cases, together tallying 124 cases out of the global total of 145 cases. All other countries have case counts in the single digits.

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Registry for Polio Survivors

- <u>https://www.conemaugh.org/apps/postpolio/</u>
- The John P. Murtha Neuroscience and Pain Institute, Johnstown, Pennsylvania, launched an <u>online registry of polio survivors</u> to promote research about the late effects of polio and post-polio syndrome.
 5-10 minutes of on-line questions Your identity is kept confidential

Post-Polio Health International sponsored research 2010

- PHI received six Phase 1 applications for its next award to be given in late 2010. The submissions, from Brazil, Israel, United States and Sweden, will be reviewed by an expert panel that includes polio survivors to determine which requests will be asked to submit Phase 2 requirements.
- THE FIFTH AWARD (2009) PHI awarded \$25,000 to team from University of Insubria, Varese, Italy, led by Antonio Toniolo, MD, PhD, Professor of Medical Microbiology and Virology. The study, <u>Persisting Noninfectious</u> <u>Fragments of Poliovirus in PPS Patients: Virus Detection and Susceptibility to Antiviral</u> <u>Drugs</u>, will complete the sequencing of the genome of persistent fragments of poliovirus strains and compare them to wild-type polioviruses.
- RESULTS: low level PV can persist for decades in polio survivors, but there is no clear link to PPMA syndrome. Further research is ongoing.
- THE FOURTH AWARD (2007) <u>PHI Grant Awarded to team at University of Arkansas for Medical Sciences (UAMS)</u> for Pilot Study to Identify PPS Biomarker. The researchers propose to determine whether there is a unique signature, or disease biomarker, in the immune system of individuals with post-polio syndrome (PPS) that would enable a more definitive diagnosis of PPS.
- RESULTS: PPMA subjects have higher levels of antibodies and regulatory T cells circulating in their blood than controls. Polio survivors without PP symptoms have variable levels—some close to the PPMA individuals, some close to the non-polio controls.

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Post-Polio Health International sponsored research 2011

- \$25,000 each to:
- Dept of PMR at Hadassah Medical Center, Jerusalem (Meiner)

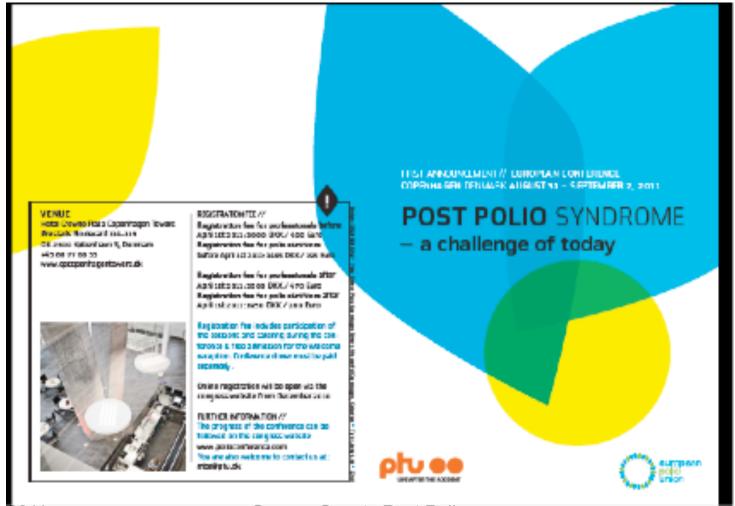
To examine demographic, medical, socioeconomic, occupational, and functional data on 250 polio survivors (Jews and Arabs) and in age and gender-matched controls. 50 from the polio group will also receive group or individual rehab twice a week for 6 weeks.

- Dept of PMR at University of Michigan, Ann Arbor (Kalpakjian)
 The Role of Oral Glutathione in Improvement of Health Outcomes Among Persons with Late Effects of Poliomyelitis.
 20 polio survivors will be monitored for subjective and objective changes.
- Neither study has been posted yet to ClinicalTrials.gov

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This Year



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WHY THE NEED TO INCREASE AWARENESS?

- Polio survivors report poorer functional status and health-related quality of life, than nonpolios.
- The life-altering effects of PPMA have not been adequately addressed by health care providers.
- Many publications indicate that polio survivors are best served in multidisciplinary clinics staffed by knowledgeable professionals.

Kudos to the OC PPMA Support Group

- Email from Baldwin Keenan 3/11/2011
- In the first quarter of 2012, probably February, a group of us will be asked to participate with physicians and other polio specialists in a Webinar to Kaiser physicians which will be CME accredited. Dr. Phan, their physiatrist in Downey will likely lead the Webinar.

This PPS-CME Webinar will be ongoing and expanded year by year.

A DVD of the Webinar will be made available to non Kaiser Physicians. I do not know if some of the professional medical academies would be willing to give CME credit for doctors who view the DVD and respond to a accompanying test. Kaiser will not be offering non Kaiser docs CME credit.

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I Believe the Standard Guidelines Still Hold

- Make sure your symptoms are polio related and not due to other neurologic, orthopedic, or medical/ medicine issues.
- Use Rehab to develop a program of appropriate nonfatiguing exercise and reconditioning, assistive devices, pacing, and finding your limit.
- Do not push past the limit of pain and fatigue.
- No one is talking "Conserve to Preserve".
- Everyone needs a good PCMD, knowledgeable PT, and attention to good general health (weight control, exercise, assistive devices, relaxation training, sleep hygiene, emotional health).

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We Need More Recognized Guidelines for Treatment as well as Diagnosis

- Prescribing Exercise for Common Conditions
- Exercising With Polio or Post-Polio Syndrome: Prescription for Health
- American College of Sports Medicine
- Posted: 04/14/2010
- <u>www.exerciseismedicine.org</u>
- Let's also remember the widely reprinted March of Dimes guidelines from the 2000 Warm Springs meeting.
- http://www.marchofdimes.com/files/PPSreport.pdf

New Publications

- In the past 12 months there have been 25 new publications about post polio in the medical literature—
 - 3 review articles of post-polio syndrome
 - **10 dealing with natural history**
 - 6 dealing with treatment issues
 - 2 with fatigue
 - 1 with pain
 - 1 with swallowing
 - 1 with falls
 - 1 review of treatment options
 - 4 dealing with investigations of pathophysiology

3 dealing with orthopedic surgeries

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Review Articles

- <u>Post-polio syndrome--polio's legacy.</u>
- Bridgens R, Sturman S, Davidson C; British Polio Fellowship's Expert Panel.
- Clin Med. 2010 Jun;10(3):213-4.
- <u>Mayo Clinic office visit. Post-polio syndrome. An interview with Anthony Windebank,</u> <u>M.D.</u>
- Windebank A.
- Mayo Clin Womens Healthsource. 2010 Aug;14(8):6.
- <u>Post-polio syndrome: unraveling the mystery.</u>
- LaRocco SA.
- Nursing. 2011 Feb;41(2):26-9; quiz 29-30. Review.

Natural History and Diagnosis

- Analysis of long-standing nociceptive and neuropathic pain in patients with post-polio syndrome. .
- Werhagen L, Borg K.
- J Neurol. 2010 Jun;257(6):1027-31. Epub 2010 Mar 30. •
- [Oropharyngeal dysphagia secondary to post-polio syndrome]. ٠
- Terré-Boliart R, Portell-Soldevila E.
- Rev Neurol. 2010 May 1;50(9):570-1. Spanish. ٠
- The post polio patient does not necessarily have the post polio syndrome. ٠
- Laban MM.
- Arch Phys Med Rehabil. 2010 Jun;91(6):966.
- Analysis of sleep characteristics in post-polio syndrome patients.
- Silva TM, Moreira GA, Quadros AA, Pradella-Hallinan M, Tufik S, Oliveira AS.
- Arg Neuropsiguiatr. 2010 Aug;68(4):535-40.
- Psychological resilience and depressive symptoms in older adults diagnosed with post-polio syndrome.
- Pierini D, Stuifbergen AK.
- Rehabil Nurs. 2010 Jul-Aug;35(4):167-75.

May 15, 2011 Baseme patterns of bone scintigraphy in patients with established post-poliomyelitis paralysis. • Marafi FA, Al-Said Ali A, Esmail AA, Elgazzar AH.

continued

- Post polio syndrome: fatigued patients a specific subgroup?
- Östlund G, Wahlin Å, Sunnerhagen KS, Borg K.
- J Rehabil Med. 2011 Jan;43(1):39-45.
- Functioning of the upper extremity in persons with late polio.
- Sunnerhagen KS, Lundgren-Nilsson A, Willén C.
- Eur J Neurol. 2011 Feb;18(2):354-8. doi: 10.1111/j.1468-1331.2010.03156.x.
- The role of ultrasonography in the diagnosis of gluteal muscle contracture.
- Li Q, Lingyan Z, Yan L, Yulan P.
- Skeletal Radiol. 2011 Feb;40(2):215-21. Epub 2010 Feb 6.
- Estimation of accuracy of patient-specific musculoskeletal modelling: case study on a post polio residual paralysis subject.
- Dao TT, Marin F, Pouletaut P, Charleux F, Aufaure P, Ho Ba Tho MC.
- Comput Methods Biomech Biomed Engin. 2011 Apr 1:1. [Epub ahead of print]

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Treatment

- Immunoglobulin responsive chronic pain.
- Goebel A.
- J Clin Immunol. 2010 May;30 Suppl 1:S103-8. Review.
- [Treatment on fatigue of patients with postpolio syndrome. A systematic review].
- Aguila-Maturana AM, Alegre-De Miquel C.
- Rev Neurol. 2010 May 16;50(10):595-602. Review. Spanish.
- Effectiveness of an online fatigue self-management programme for people with chronic neurological conditions: a randomized controlled trial.
- Ghahari S, Leigh Packer T, Passmore AE.
- Clin Rehabil. 2010 Aug;24(8):727-44. Epub 2010 Jun 11.
- Update on current and emerging treatment options for post-polio syndrome.
- Farbu E.
- Ther Clin Risk Manag. 2010 Jul 21;6:307-13
- Dysphagia and dysphonia among persons with post-polio syndrome a challenge in neurorehabilitation.
- Söderholm S, Lehtinen A, Valtonen K, Ylinen A.
- Acta Neurol Scand. 2010 Nov;122(5):343-9.

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Surgical Treatment

- <u>Microvascular free functioning gracilis transfer with nerve transfer to establish elbow</u> <u>flexion.</u>
- Kay S, Pinder R, Wiper J, Hart A, Jones F, Yates A.
- J Plast Reconstr Aesthet Surg. 2010 Jul;63(7):1142-9. Epub 2009 Jun 13.
- [Reconstruction of quadriceps femoris muscle function with muscle transfer].
- Fansa H, Meric C.
- Handchir Mikrochir Plast Chir. 2010 Aug;42(4):233-8. Epub 2010 Mar 16. German.
- <u>Spinal anaesthesia guided by computed tomography scan in a patient with severe</u> <u>post-polio sequelae.</u>
- Bordes J, Gaillard PE, Lacroix G, Palmier B.
- Br J Anaesth. 2010 Nov;105(5):702-3.

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Pathophysiology

- Particle agglutination method for poliovirus identification.
- Arita M, Masujima S, Wakita T, Shimizu H.
- J Vis Exp. 2011 Apr 20;(50). pii: 2824. doi: 10.3791/2824.
- <u>Concomitant CNS pathology in a patient with amyotropic lateral sclerosis following poliomyelitis in childhood.</u>
- Casula M, Steentjes K, Aronica E, van Geel BM, Troost D.
- Clin Neuropathol. 2011 May-Jun;30(3):111-7.
- <u>Genotoxic assessment in peripheral blood lymphocytes of post-polio individuals using sister</u> <u>chromatid exchange analysis & micronucleus assay.</u>
- Bhattacharya SK, Saraswathy R, E S.
- Hum Exp Toxicol. 2010 Jul 14.
- Leukocyte myeloperoxidase and pathogenesis of the post-polio syndrome.
- Movitz C, Bergström T, Borg K, Hellstrand K, Lycke E, Lycke J.

May Scand Infect Dis. 2010 Dec;42(10 12):958-60, Epubration Oct 18 Support Group

Review of Treatment Trials for Fatigue

- [Treatment on fatigue of patients with postpolio syndrome. A systematic review] [Article in Spanish]
- <u>Aguila-Maturana AM, Alegre-De Miquel C</u>.
- Rev Neurol. 2010 May 16;50(10):595-602.
- INTRODUCTION: Fatigue is the most common symptom and the most disabling in patients with post-polio syndrome.
- AIM: To analyze the effectiveness of various treatments used to improve fatigue syndrome patients post-polio.
- MATERIALS AND METHODS: Systematic review. Is defined a bibliographic search strategy in Medline (from 1961), EMBASE (from 1980), ISI Web of Knowledge and Cochrane Library, Cochrane Central Register of Controlled Trials (CENTRAL), AMED (January 1985), EMI and Physiotherapy Evidence Database (PEDro) until February 2008, the population defined (post-polio syndrome patients) and intervention (any treatment for fatigue in these patients). Outcome were selected as different scales of fatigue and fatigue or vitality dimension scales quality of life. Clinical trials were selected.
- RESULTS: We retrieved 396 articles, of which 23 were analyzed in detail. Finally, 19 were included in the analysis, a total of 705 patients.
- CONCLUSIONS: Lamotrigine, bromocriptine, aerobics and flexibility exercises, hydrokinesitherapy and technical aids are treatment techniques that reduce more fatigue in these patients.

May 15, 2011

Follow up on Fatigue Trial

- Clin Rehabil. 2010 Aug;24(8):727-44. Epub 2010 Jun 11. .
- Effectiveness of an online fatigue self-management programme for people with chronic neurological conditions: a randomized controlled trial.
- Ghahari S. Leigh Packer T. Passmore AE.
- Source
- Centre for Research into Disability and Society, Curtin Health Innovation Research Institute, Curtin University. Perth, Australia. setareh.ghahari@gmail.com
- Abstract
- **OBJECTIVE:**
- To evaluate an online fatigue self-management programme in a sample of adults with chronic neurological conditions.
- DESIGN:
- Randomized controlled trial.
- SETTING:
- Online fatigue self-management programme delivered across Australia.
- PARTICIPANTS:
- Ninety-five people with fatigue secondary to multiple sclerosis, Parkinson's disease or post-polio syndrome.
- INTERVENTIONS:
- An online fatigue self-management programme, an information-only fatigue self-management programme and a control group.
- MAIN MEASURES:
- Groups were compared at pre test, post test and at three months on primary outcomes using the Fatigue Impact Scale, Activity Card Sort and Personal Wellbeing Index.
- **RESULTS:**
- With the exception of the Personal Wellbeing Index at post test (F = 3.519; P =0.034) and the Physical Subscale of the Fatigue Impact Scale at follow-up (F = 3.473; P =0.035) there were no significant differences between the three groups on primary outcomes. Post-hoc testing showed the differences to be between the information-only and control groups (P = 0.036 and P = 0.030 respectively). Improvement in the information-only group was unexpected but appears to be similar to results of other online interventions. The fatigue self-management and information-only groups performed better than the control group secondary outcome measures. Low **obvariable erables interventions** were time on the Fatigue Impact Scale and the Activity Card Sort (P<0.05). The control group showed no improvements over time.

Pain

- J Neurol. 2010 Mar 30. [Epub ahead of print]
- Analysis of long-standing nociceptive and neuropathic pain in patients with post-polio syndrome.
- Werhagen L, Borg K.
- Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institutet Danderyds Hospital, Stockholm, Sweden, lars.werhagen@ki.se.
- Abstract
- The purpose of this study was to analyze pain, both nociceptive and neuropathic, in patients with post-polio syndrome (PPS) and relate the pain to age at the initial polio infection, age at examination, to gender and disability. The study was conducted in a university hospital department.
- Patients with PPS were interviewed at their regular visits about pain, its character, intensity and localization. A clinical examination, including a thorough neurological examination, was performed. Data included age at time of polio infection, age at time of examination and gender. Pain intensity was measured with the VAS-scale and walking capability by the WISCI-scale.
- One hundred sixty-three (88 women, 75 men) patients were included in the study. Pain was present in 109 (67%). Pain was more frequently reported by women (82%) than by men (49%). 96 patients experienced nociceptive pain, 10 patients both neuropathic and nociceptive pain and three experienced pure neuropathic pain. Half of the patients with pain experienced pain in more than one body region.
- When neuropathic pain was present, another additional neurological disorder was diagnosed.
- Pain was more often found in younger patients (around 70%) than in older patients (around 50%).
- In summary pain is common in patients with PPS and most patients experienced nociceptive pain. Women have pain more often than men. Older patients experience pain more seldom than younger patients. Age at time of primary polio infection is important for the development of pain. When neuropathic pain is present, it is important to proceed with neurological examination to find an adequate diagnosis.
 May 15, 2011

Support Group

IVIG and Pain Management

- J Clin Immunol. 2010 May;30 Suppl 1:S103-8.
- Immunoglobulin responsive chronic pain.
- <u>Goebel A</u>.
- Source
- Pain Research Institute, 3rd Floor, Clinical Sciences Centre, Liverpool University, Liverpool, UK. andreasgoebel@rocketmail.com
- Abstract
- INTRODUCTION:
- Over the last 15 years, clinical and experimental data have emerged that suggest that peripheral and central, glialmediated neuroimmune activation is both necessary and sufficient to sustain chronic pain. Immune modulation appears to be, therefore, a possible new therapeutic option.

• MATERIALS AND METHODS:

 The Medline database and international trial registry databases were searched using the keywords "intravenous immunoglobulin" or "IVIG," "pain" or "chronic pain," "neuropathic pain," "CRPS," "complex regional pain syndrome" or "fibromyalgia."

RESULTS:

- Evidence from RCTs suggest that IVIG is effective to reduce pain in complex regional pain syndrome (low-dose IVIG) and post-polio syndrome (high-dose IVIG), and open trials have suggested efficacy in additional pain conditions.
- CONCLUSION:
- IVIG therapy may emerge as a novel treatment modality for refractory cases. However, before this drug can be confidently used by clinicians, important questions need to be answered concerning optimal treatment doses, duration of treatment, and its effect on function and quality of life.

May 15, 2011

J Rehabil Med. 2010 Nov;42(10):908-15.

Circumstances and consequences of falls in polio survivors.

Bickerstaffe A, Beelen A, Nollet F.

Source

Department of Rehabilitation AMC, Amsterdam, The Netherlands. a.bickerstaffe@amc.uva.nl

- Abstract
- OBJECTIVES:
- Many polio survivors have symptoms that are known risk factors for falls in elderly people. This study aims to determine the: (i) frequency; (ii) consequences; (iii) circumstances; and (iv) factors associated with falls in polio survivors.
- METHODS:
- A survey was conducted among 376 polio survivors. Participants completed a falls history questionnaire and additional information was obtained from their medical files.
- RESULTS:
- Of the 305 respondents, 74% reported at least one fall in the past year and 60% two or more. Sixteen percent of fallers described a major injury after a fall in the last year and 69% reported fear of falling. One-third of fallers had reduced the amount they walked because of their fear of falling. Most reported falls in a familiar environment (86%), during ambulation (72%) and in the afternoon (50%).
- Quadriceps weakness of the weakest leg (Medical Research Council (MRC) ≤ 3), fear of falling and complaints of problems maintaining balance were independently associated with both falls and recurrent falls,
- while increasing age and medication use were not.
- CONCLUSION:
- The high rate of falls and consequences thereof, merit the implementation of fall intervention strategies. To maximize effect, they should be tailor-made and target the fall mechanisms specific to polio survivors

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Swallowing and Sleep The Bulbar Muscles and Brainstem

- Acta Neurol Scand. 2010 Nov;122(5):343-9. doi: 10.1111/j.1600-0404.2009.01315.x.
- Dysphagia and dysphonia among persons with post-polio syndrome a challenge in neurorehabilitation.
- <u>Söderholm S, Lehtinen A, Valtonen K, Ylinen A</u>.
- Source
- Käpylä Rehabilitation Centre, Finnish Association of People with Mobility Disabilities, Helsinki, Finland. sinikka.soderholm@kolumbus.fi
- Abstract
- OBJECTIVE:
- To study the occurrence of dysphagia and dysphonia in persons with post-polio syndrome admitted into the centre for neurological rehabilitation in Finland.
- MATERIALS AND METHODS:
- Fifty-one persons with post-polio syndrome who were rehabilitated at Käpylä Rehabilitation Centre, Helsinki, Finland, in 2003-2004 were interviewed on problems with swallowing and voice production. Pulmonary function testing and grip strength measurement were performed. A clinical assessment of oral motor and laryngeal functions was carried out for those who reported daily problems with voice production or swallowing.
- RESULTS:
- Fifteen persons (29.4%) reported daily problems with swallowing or voice production. In the clinical assessment, the most commonly observed deficits in swallowing included decreased pharyngeal transit (n = 13) and the food catching in the throat (n = 4). The disturbance of co-ordination of breathing and voice production was seen in 12 persons. There were no significant differences in any of the potential predictors between the groups.
- CONCLUSIONS:
- Professionals need to be aware of the routine evaluation of dysphagia and dysphonia in patients with post-polio syndrome.

May 15, 2011

- Arq Neuropsiquiatr. 2010 Aug;68(4):535-40.
- Analysis of sleep characteristics in post-polio syndrome patients.
- <u>Silva TM, Moreira GA, Quadros AA, Pradella-Hallinan M, Tufik S, Oliveira AS</u>.
- Department of Neurology, Escola Paulista de Medicina, Universidade Federal de São Paulo, São Paulo, SP, Brazil. tatimsilva@gmail.com
- OBJECTIVE:
- To analyze sleep patterns in PPS patients.
- METHOD:
- Sixty patients (mean age 46.8+/-11.3 years) at the Federal University of São Paulo (UNIFESP/ EPM) complaining of sleep disturbances were evaluated by means of polysomnography, performed at the Sleep Institute.
- RESULTS:
- Sleep efficiency was lower due to high sleep latency and arousal index. The apnea and hypopnea index (AHI) and the periodic limb movements (PLM) index were higher. Sleep architecture was also impaired. There were no abnormalities of oxygen saturation, carbon dioxide levels, respiratory rate or heart rate.
- CONCLUSION:
- New post-polio sleep disturbances were isolated symptoms. It appears that these symptoms were
 not due to post-polio features, but rather, that they were due to dysfunction of the surviving motor
 neurons in the brainstem. Abnormal dopamine production, which is responsible for many sleeprelated breathing disorders and abnormal movements, may also have been implicated in the
 present findings.

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Are Polio Survivors Depressed?

- Rehabil Nurs. 2010 Jul-Aug;35(4):167-75.
- Psychological resilience and depressive symptoms in older adults diagnosed with postpolio syndrome.
- <u>Pierini D</u>, <u>Stuifbergen AK</u>.
- Source
- University of Texas at Austin, School of Nursing, Austin, TX, USA. dianapierini@utexas.edu
- Abstract
- Depression is a serious comorbidity in people with disabilities; however, few studies have focused on depressive symptoms in older adults with post-polio syndrome (PPS). This study used a resilience conceptual framework that focused on patient psychosocial strengths to investigate the relationship between psychological resilience factors (e.g., acceptance, self-efficacy, personal resources, interpersonal relationships, self-rated health, spiritual growth, stress management) and depressive symptoms in a large sample (N = 630) of people older than 65 years who were diagnosed with PPS.
- Forty percent of the sample scored > or = 10 on the Center for Epidemiologic Studies Short Depression Scale (CES-D10), which is a higher percentage than what has been previously cited in other studies; however, 53% of the sample had good or excellent self-rated health, suggesting psychological resilience. Depression scores were regressed on seven selected resilience factors after controlling for functional limitations. Four of the seven variables accounted for 30% of the variance in depressive symptoms, with spiritual growth representing the main predictor (beta = -. 26). The implications for rehabilitation nurses in developing a patient-strengths perspective in the assessment and counseling of older adults with PPS are discussed.

May 15, 2011

Update on current and emerging treatment options for post-polio syndrome. Farbu E. Ther Clin Risk Manag. 2010 Jul 21;6:307-13

- The basic principle of management of PPS lies in physical activity, individually tailored training programs, and lifestyle modification.
- Muscle weakness and muscle pain may be helped with specific training programs, in which training in warm water seems to be particularly helpful.
- Properly fitted orthoses can improve the biomechanical movement pattern and be energy-saving.
- Fatigue can be relieved with lifestyle changes, assistive devices, and training programs.
- Respiratory insufficiency can be controlled with noninvasive respiratory aids including biphasic positive pressure ventilators.
- Pharmacologic agents like prednisone, amantadine, pyridostigmine, and coenzyme Q10 are of no benefit in PPS.
- Intravenous immunoglobulin (IVIG) has been tried in three studies, all having positive results. IVIG could probably be a therapeutic alternative, but the potential benefit is modest, and some important questions are still unanswered, in particular to which patients this treatment is useful, the dose, and the therapeutic interval.

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Cochrane Review

Treatment for postpolio syndrome

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Search strategy

- We searched the following databases on 1 October 2010: Cochrane Neuromuscular Disease Group Specialized Register, the Cochrane Central Register of Controlled Trials, MEDLINE, EMBASE, PsycINFO and CINAHL Plus from inception to September 2010.
- Selection criteria
- Randomised and quasi-randomised trials of any form of pharmacological or non-pharmacological treatment for people with PPS. The primary outcome was self-perceived activity limitations and secondary outcomes were muscle strength, muscle endurance, fatigue, pain and adverse events.

Main results

Nine pharmacological (modafinil, intravenous immunoglobulin, pyridostigmine, lamotrigine, amantadine, prednisone) and three non-pharmacological (muscle strengthening, rehabilitation in a warm climate (i.e. temperature ± 25°C, dry and sunny) and a cold climate (i.e. temperature ± 0°C, rainy or snowy), static magnetic fields) studies were included in this review. None of the included studies was completely free from any risk of bias and the most prevalent risk of bias was lack of blinding.

Authors' conclusions

 Due to insufficient good quality data and lack of randomised studies it is impossible to draw definite conclusions on the effectiveness of interventions for PPS. Results indicate that IVIG, lamotrigine, muscle strengthening exercises and static magnetic fields may be beneficial but need further investigation.
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Stem Cells

 To date 38 the Sanford Consortium affiliated faculty have received grants from CIRM, totaling more than \$50,000,000. For grant information, please visit CIRM's Web site at: www.cirm.ca.gov/RFA/default.asp

New Faculty Grant Awards Sheng Ding, Ph.D. Sheng Ding, Ph.D., is an associate professor in the Chemistry and Cell Biology Departments at The Scripps Research Institute. His laboratory's main research focus is to develop and integrate chemical and functional genomic tools to study stem cell biology and regeneration.

- Over the past few years, Ding's laboratory has constructed large combinatorial chemical libraries and arrayed cDNA and RNAi libraries. Furthermore, it has developed and implemented high throughput cellular screens of these libraries to identify small molecules and genes which can control stem cell fate in various systems.
- The main research focus of the Ding laboratory is to develop and integrate chemical and functional genomic tools to study stem cell biology and regeneration.
- Recent advances in stem cell biology may make possible new approaches for the treatment of a number
 of diseases including cardiovascular disease, neurodegenerative disease, musculoskeletal disease,
 diabetes and cancer. These approaches could involve cell replacement therapy and/or drug treatment to
 stimulate the body?s own regenerative capabilities by promoting survival, migration/homing,
 proliferation, differentiation and reprogramming of endogenous stem/progenitor cells or more
 differentiated cells. However, such approaches will require identification of renewable cell sources of
 engraftable functional cells, an improved ability to manipulate their proliferation and differentiation, as
 well as a better understanding of the mechanisms that control their fate/function.

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However

- A Romanian baby died after her stem cells were injected at a clinic in Düsseldorf
- Published on October 26, 2010 by Financial Advisor
- Most stem cell clinic in Europe is at the center of a scandal after the death of a Romanian child of 18 months. According to The Telegraph, reputedly died after receiving an injection in the brain controversial.
- XCell-Center Clinical Treatment involves taking bone marrow from patients, harvesting stem cells from bone marrow and then their reinjection in other parts of the body including the brain, spine and neck.
- Boy of 18 months, whose parents lived in Italy, Romanian, was injected into the brain stem cells and subsequently died.

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WHAT WE ALREADY KNOW

- New symptoms in a polio survivor are PPS only about 1/3 of the time.
- New symptoms may be due to another medical or neurological illness or to orthopedic problems, which must be identified and treated.
- Treatment of other illnesses in a polio survivor must be monitored relative to the sensitivities of PPS (eg. surgery, chemotherapy, use of cholesterol lowering medication).
- Polio survivors with symptoms of PPS must take care to modify lifestyle; avoid overuse; use assistive devices and bracing if appropriate; control weight gain, sleep problems, stress, and pain; and engage in non-fatiguing exercise for strength and conditioning. Many studies have shown that success in these areas can halt progression of PPS symptoms and promote improvement of 1-2% per year.

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Resources

WWW.POST-POLIO.ORG WWW.NCBI.NLM.NIH.GOV/ ENTREZ (PUBMED)

WWW.CLINICALTRIALS.GOV

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