

ABSTRACTS

Post Polio Syndrome – a Challenge of Today European Conference

AUGUST 31 – SEPTEMBER 2, 2011, COPENHAGEN, DENMARK

WELCOME TO COPENHAGEN

Dear Colleagues,

Initiated by the European Polio Union (EPU) and organized by the Danish Society of Polio and Accident Victims (PTU) the 3 day Conference 'Post Polio Syndrome – A Challenge of Today' is being held from August 31 to September 2 2011 in Copenhagen, Denmark.

Post polio syndrome is a highly prevalent condition in the European Union (EU) with an estimated 1 million survivors of polio. Most of them were affected by acute polio during the epidemics in the 20th century before vaccination became available. It was only in 2002 that Europe was officially declared free of polio by the World Health Organisation. The EU however also accommodates a large number of immigrants from all over the world who were affected by polio in their country of origin, and many of them are still young.

The EPU was founded in 2003 and at present consists of 19 polio patient organisations from 13 European countries and strives for better recognition of and care for the post-polio syndrome at the European level. The large variation in medical and rehabilitation care in Europe for polio survivors suffering from the late decline in functioning due to the post-polio syndrome was a major concern for EPU and the motive for this conference.

This conference is a historical achievement. For the first time polio survivors, health care providers and researchers are brought together on this topic from all over Europe. To boost awareness, knowledge and care for post polio syndrome, and to promote European cooperation and to stimulate cooperative research this meeting is being held. This supplement of Journal of Rehabilitation Medicine contains all abstracts of the conference.

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Acknowledgements:

The European Union (EPU) and The Danish Society of Polio and Accident Victims (PTU) thank the scientific committee for planning the scientific content of this conference: Frans Nollet, MD, NL (Chairman), Kristian Borg, MD, SE, Jan Lexell, MD, SE, Lise Kay, MD, DK, Marianne de Visser, MD, NL, Antonio Toniolo, MD, IT, Laura Bertolasi, MD, IT, Arzu On, MD, TR, Alain Yelnik, MD, FR, Merete Bertelsen, PT, DK, and 2 EPU representatives: Els Symons, NL, John McFarlane, IR

EPU and PTU thank all the researchers, who have contributed to the scientific content by giving speeches or submitting abstracts and presenting by posters.

EPU and PTU thank the funds who have supported the conference financially:

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European Polio Union

- An umbrella organization for polio organizations in Europe

60 percent of all people who have had Polio will develop Post Polio Syndrome. This concerns approximately 700,000 Europeans. EPU strives for all Europeans with Post Polio Syndrome to have the best possibilities to lead full active, independent and integrated lives.

Our objectives are:

- Encourage coordinated research about Post Polio Syndrome
- Create an international web site for data in relation to polio and Post Polio Syndrome
- Produce a validated information bank of positive help to arrest the deterioration of people with Post Polio Syndrome
- Campaign to ensure the need for continued polio-vaccination programs

For further information about EPU or to make a donation, please visit our website: www.europeanpolio.eu



CONTENT

	Page No.	Abstract No.
Programme	5	
List of Poster	9	
General Perspectives of Polio	10	1–3
International Networking	11	4
Pathophysiology, Pharmacological Research and Treatment (for Polio Survivors)	12	5–8
Pathophysiology, Pharmacological Research and Treatment (for Professionals)	14	9–12
Patient Assessment	16	13–16
Free Papers	18	17–20
Symptoms and Management 1 (for Polio Survivors)	20	21–24
Symptoms and Management 2 (for Polio Survivors)	22	25–28
Symptoms and Management 3 (for Polio Survivors)	24	29–32
Free Papers	26	33–36
Outcome Measures	28	37–42
Symptoms and Management 1 (for Professionals)	31	21–24
Symptoms and Management 2 (for Professionals)	32	25, 26, 28, 43
Free Papers	33	44–47
Aging	35	27, 31, 32, 48
Mobility	36	29, 49, 50
Exercising	38	51–53
Orthotics	40	54, 55
Free Papers	41	56–59
Rehabilitation	43	60–63
Awareness of Post polio in the Political and Social System	45	64–66
Poster presentations at Post polio Conference in Copenhagen	47	67–98
Author Index	63	

3 weeks rehabilitation in Copenhagen

PTU Rehabilitation Center offers specialized multidisciplinary rehabilitation treatment for persons with polio and other physical disabilities

The 3 week program comprises:

- Assessment and treatment by neurologist, physiotherapist, occupational therapist, psychologist
- Individualized exercising programme
- Group exercises sessions
- Technical aids counseling
- Exercise and relaxation in warm pool
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- Free use of technical aids
- Free use of massage chair
- Accommodation and all meals

For more information
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www.ptu.dk/english

or contact PTU:
mail: ptu@ptu.dk /
phone: +45 3673 9000

ptu ●●
LIFE AFTER THE ACCIDENT

PROGRAMME**WEDNESDAY, AUGUST 31, 2011****8.30****Registration opens****9.45–10.00***Coffee with bread***10.00–10.40***Opening Ceremony***10.40–12.00****General Perspectives of Polio.** *Moderators: Kristian Borg & Holger Kallehauge*

Progress of the eradication of polio from WHO's perspective (Summary 1)

Rebecca Martin

The story behind the polio eradication campaign (Summary 2)

Peter Bundgaard Rotary

Post Polio Syndrome, overview of current knowledge (Summary 3)

Frans Nollet

Questions and discussion

12.00–13.00*Lunch and Exhibition/Poster Viewing***13.00–14.30 (Primarily for polio survivors)****International Networking.** *Moderators: Els Symons & Aadje de Groot*Improving worldwide networking to improve the lives of all survivors (Summary 4) *Joan Headley and Johan Bijttebier***13.00–14.30 (Primarily for health care professionals)****Pathophysiology, Pharmacological Research and Treatment.***Moderators: Marianne de Visser & Katharina Stibrant Sunnerhagen**This session is sponsored by GRIFOLS*

Pathogenesis of PPS and persistence of poliovirus genomes (Summary 9)

Antonio Toniolo

Immune modulation and a potential biomarker (Summary 10)

Kristian Borg

Treatment for PPS: Results from a Cochrane review (Summary 11)

Fieke Koopman

Revised EFNS guidelines for diagnosis and management of post-polio syndrome (Summary 12)

Elisabeth Farbu

Questions and discussion

14.30–15.00*Coffee/Exhibition and Poster viewing***15.00–16.30 (Primarily for polio survivors)****Pathophysiology, Pharmacological Research and Treatment.** *Moderators: Lise Kay & Els Symons*

Pathogenesis of post polio syndrome and persistence of poliovirus genomes (Summary 5)

Antonio Toniolo

Research methodology (Summary 6)

Fieke Koopmann

Pharmacological treatment and medical precautions (Summary 7)

Kristian Borg

Personal experience with IVIG treatment (Summary 8)

Esther Boserup

Questions and discussion

14.30–15.00 (Primarily for health care professionals)**Patient Assessment.** *Moderator: Frans Nollet & Elisabeth Farbu*

Diagnostic tools (Summary 13)

Laura Bertolasi

Electrodiagnostic studies: What, When, Why, Why not? (Summary 14)

Arzu On

Differential diagnosis (Summary 15)

Marianne de Visser

Rehabilitation assessment (Summary 16)

Frans Nollet

Questions and discussion

18.00–19.00*Reception at City Hall of Copenhagen*

THURSDAY, SEPTEMBER 1, 2011

09.00–10.00 (Primarily for polio survivors)

Free Papers. Moderators: *Aadje de Groot & Kristian Borg*

- Australia's polio health and wellness retreat (Summary 17)
- The warm embrace of peer support (Summary 18)
- Disuse osteoporosis in the patients with post polio syndrome (Summary 19)
- Cycle to walk polio eradication (Summary 20)

*Mary-ann Liethof
Anne Shahanan
Jülide Öncü
Ramesh Ferris*

09.00–10.00 (Primarily for health care professionals)

Free Papers. Moderators: *John McFarlane & Judith Glaser*

- A needs-based Rasch-standard Quality of Life scale (Summary 33)
- An exploration of different coping strategies (Summary 34)
- Never second best? Shaping and reconstruction of identity (Summary 35)
- Factors influence the quality of life of poliomyelitis (Summary 36)

*Alan Tennant
Anne-Marie Quincey
Anne-Kristine Schanke
Anita Atwal*

09.00–10.00 (Primarily for health care professionals)

Free Papers. Moderators: *Antonio Toniolo & Fieke Koopman*

- Resistance training in combination with IVIG treatment (Summary 44)
- Intravenous immunoglobulin for post-polio syndrome (Summary 45)
- Physiotherapy as part of a multidisciplinary rehabilitation (Summary 46)
- Home ventilator user survey: A peek inside vent users' thoughts (Summary 47)

*Katarina Skough
Laura Bertolasi
Susse Broberg
Barbara Rogers*

10.00–10.30

Coffee/Exhibition and Poster Viewing

10.30–12.00 (Primarily for polio survivors)

Symptoms and Management 1. Moderators: *Lise Kay & Holger Kallehaug*

- Orthopedic surgery in polio survivors (Summary 21)
- Anesthesia issues for polio survivors (Summary 22)
- Respiration and sleep (Summary 23)
- Speech and swallowing (Summary 24)
- Questions and discussion

*Anders Stenström
Selma Calmes
Michael Laub
Svend Prytz*

10.30–12.00 (Primarily for health care professionals)

Outcome Measures. Moderators: *Marianne de Visser & Arzu On*

- International classification of functioning, disability and health (Summary 37)
- Muscle strength measurement (Summary 38)
- Outcome measures for fatigue (Summary 39)
- Outcome measures for pain (Summary 40)
- Outcome measures for physical functioning (Summary 41)
- Outcome measures for participation and quality of life (Summary 42)
- Questions and discussion

*Frans Nollet
Anita Beelen
Gunilla Östlund
Troels Staehelin Jensen
Merel Brehm
Katharina Stibrant Sunnerhagen*

10.30–12.00 (Primarily for health care professionals)

Aging. Moderators: *Jülide Öncü & Laura Bertolasi*

- General perspective of aging (Summary 48)
- Participation in Society (Summary 32)
- Impact of comorbidity, aging and lifestyle-related factors in polio survivors (Summary 29)
- Psychological aspects of polio survivors through their life experience (Summary 31)
- Questions and discussion

*Kirsten Avlund
Jan Lexell
Irene Tersteeg
Alain Yelnik*

12.00–13.00

Lunch and Exhibition/Poster Viewing

13.00–14.30 (Primarily for polio survivors)**Symptoms and Management 2.** Moderators: *Kristian Borg & John McFarlane*

Fatigue - Symptoms and management (Summary 25)

Pain in polio survivors (Summary 26)

Impact of comorbidity, aging and lifestyle-related factors in polio survivors (Summary 27)

Voiding and bowel problems (Summary 28)

Questions and discussion

*Gunilla Östlund**Katharina Stibrant Sunnerhagen**Irene Tersteeg**Lise Kay***13.00–14.30 (Primarily for health care professionals)****Symptoms and Management 1.** Moderators: *Alain Yelnik & Antonio Toniolo*

Orthopedic surgery in polio survivors (Summary 21)

Anesthesia issues for polio survivors (Summary 22)

Respiration and sleep (Summary 23)

Speech and swallowing (Summary 24)

Questions and discussion

*Anders Stenström**Selma Calmes**Michael Laub**Svend Prytz***13.00–14.30 (Primarily for health care professionals)****Mobility.** Moderators: *Deidre Murray & Christina Brogaardh*

Falls among polio survivors (Summary 29)

Leg orthoses for polio survivors: Numerous innovations, limited evidence (Summary 49)

A systematic seating assessment (Summary 50)

Questions and discussion

*Alice Bickerstaffe**Merel Brehm**Anna-Lene Hartvigsen***14.30–15.00***Coffee/Exhibition and Poster Viewing***15.00–16.30 (Primarily for polio survivors)****Symptoms and Management 3.** Moderators: *Arzu On & Els Symons*

Falls among polio survivors (Summary 29)

Exercising for polio survivors (Summary 30)

Psychological aspects of polio survivors through their life experience (Summary 31)

Participation in society (Summary 32)

Questions and discussion

*Alice Bickerstaffe**Deidre Murray**Alain Yelnik**Jan Lexell***15.00–16.30 (Primarily for health care professionals)****Symptoms and Management 2.** Moderators: *Kristian Borg & Laura Bertolasi*

Voiding and bowel problems (Summary 28)

Fatigue – symptoms and management (Summary 25)

Pain in polio survivors (Summary 26)

Managing the complexity in daily occupations (Summary 43)

Questions and discussion

*Lise Kay**Gunilla Östlund**Katharina Stibrant Sunnerhagen**Anna Lisa Thoren Jönsson***15.00–16.30 (Primarily for health care professionals)****Exercising.** Moderators: *Anita Beelen & Gunnar Grimby*

Role of exercise (Summary 51)

Role of aerobic exercises (Summary 52)

How to target aerobic exercise training in polio survivors (Summary 53)

Questions and discussion

*Carin Willén**Jülide Öncü**Eric Voorn***16.40–17.40***Film: The Epidemic: "I don't remember anything – but I'll never forget."**Niels Frandsen***16.40–18.00****Professional networking (For health care professionals)***Scientific committee*

FRIDAY, SEPTEMBER 2, 2011

9.00–10.00

Orthotics. *Moderators: Frans Nollet and Morten Fenger*

Orthosis management (Summary 54)

Barbara Bocker

Light weight full contact carbon leg orthoses (Summary 55)

Kees Noppe

9.00–10.00

Free Papers. *Moderators: Jan Lexell & Susse Broberg*

Evaluation of the function of pelvic floor muscles (Summary 56)

Mirca Ocanhas

Natural history the poliomyelitis and post polio syndrome in Brazil (Summary 57)

Abrahamo Quadros

Fatigue in patients with post polio syndrome (Summary 58)

Anita Beelen

Experiences in daily occupations of immigrants with late effects of polio (Summary 59)

Iolanda Santos Tavares

10.00–10.30

Coffee/Exhibition and Poster Viewing

10.30–12.00

Rehabilitation. *Moderators: Gunnar Grimby & Alain Yelnik*

Rehabilitation in a public health perspective (Summary 60)

Claus Vinther Nielsen

Inter disciplinary teamwork (Summary 61)

Jan Lexell

The value of investigating patient perspectives (Summary 62)

Karen Schipper

Patient journey – My life with polio (Summary 63)

Sylvi Salomonsen

Questions and discussion

12.00–13.00

Lunch and Exhibition/Poster Viewing

13.00–15.00

Awareness of Post Polio in the Political and Social System.

Moderators: Ros Sinclair & Philip Rendtorff

Post polio syndrome policy in the EU (Summary 64)

Holger Kallehaug

Disability in the political arena (Summary 65)

John McFarlane

Cost effectiveness (Summary 66)

Kjeld Møller Petersen

Summary of the conference

Frans Nollet

Closure

Johan Bijttebier

15.00–15.30

Coffee

LIST OF POSTERS

Summary 67: Analyses of sleep characteristics in Post-Polio Syndrome Patients. *Tatiana Mesquita e Silva*

Summary 68: Comparison of self-reported fatigue in Post-Polio Syndrome patients and age-matched controls. *Charlotte Lucy Taylor*

Summary 69: New muscle weakness in the subclinically involved limbs in patients with poliomyelitis. *Arzu Yagiz On*

Summary 70: Relationship between lower limb muscle strength and gait performance in persons with post-polio syndrome. *Ulla-Britt Flansbjerg, Christina Brogårdh, Jan Lexell*

Summary 71: Relationships between objectively and subjectively assessed gait performance in persons with post-polio syndrome. *Christina Brogårdh*

Summary 72: The WHOQOL-BREF provides a valid measure of Quality of Life in Post-polio Syndrome. *Ian Pomeroy*

Summary 73: Post-polio syndrome and amyotrophic lateral sclerosis - similarities, differences and diagnostic dilemmas. *Ewa Matyja, Milena Laure-Kamionowska*

Summary 74: Validity and reliability of the Turkish version of Fatigue Severity Scale and Fatigue Impact Scale for Post-polio Syndrome. *Jülide Öncü*

Summary 75: Concept of an interdisciplinary polio modul programme and therapy for polio. *Axel Ruetz*

Summary 76: Benefits and Techniques of Aquatic Therapy. *Cynthia Henley, Kathryn Wollam*

Summary 77: Disabilities and working situation of immigrant with post-polio syndrome. *Linda Hou*

Summary 78: Experience with Younger Patients in a Post-Polio Clinic: A Case Series. *Judith Glaser*

Summary 79: Prescription of and satisfaction with the use of lower limb orthotic devices in persons with post-polio syndrome. *Christina Espelund*

Summary 80: A guideline for the orthotic management in patients with severe weakness or paralysis of the lower extremities. *M.A. Brehm*

Summary 81: Energy cost of walking in prior-polio patients. *Deirdre Murray*

Summary 82: Exercise therapy and cognitive behavioural therapy in post-poliomyelitis Syndrome: The FACTS-2-PPS study. *F. Koopman*

Summary 83: Voiding problems in a Danish population of polio survivors. *Lise Kay, Merete Bertelsen*

Summary 84: Reported problems in relation to operation and anesthesia a Danish population of polio survivors. *Lise Kay, Merete Bertelsen*

Summary 85: Ventilatory threshold in Post-polio-myelitis syndrome patients. *Anita Beelen*

Summary 86: Results of 5-years of Lamotrigine treatment in patients with post-polio syndrome. *Arzu Yagiz On*

Summary 87: Fractures in an aging population poliomyelitis survivors- Experience of the Post-Polio clinic In Israel. *Shapira Alex*

Summary 88: An exploration of fatigue from the perspective of people with Post-polio Syndrome. *Samantha M. Wong*

Summary 89: An exploration of the impact of Post-polio Syndrome on needs based quality of life. *Anne-Marie C. Quincey*

Summary 90: A positive turning point in life. Experiences of a comprehensive interdisciplinary rehabilitation programme in persons with post-polio syndrome. *Jan Lexell*

Summary 91: Self-perceived impairments in persons with post-polio syndrome. *Jan Lexell*

Summary 92: Self-perceived participation restrictions in persons with post-polio syndrome before and after interdisciplinary rehabilitation. *Jan Lexell*

Summary 93: Occupations that persons with post-polio syndrome perceive difficult to perform in their daily life. *Katja Appelin*

Summary 94: A Brief History of Post-Polio in The United States. *Lauro S. Halstead*

Summary 95: Post-polio Syndrome in British Columbia, Canada. *Joan Toone*

Summary 96: Polio Services Victoria: An Australian Approach to Effective Care for Polio Survivors through a "Hub and Satellite" Model. *Doran Blaise*

Summary 97: A Sociological Study: Failure of Polio Eradication Programme in India. *Ehtesham Akthar, Jamia Millia*

Summary 98: Post-Polio Syndrome: Situation in Spain and proposals for action. *Jose M. Amate, Carmen Bouza, Zuleika Saz-Parkinson, Maayken Van Den Berg, Juan M. Castellote*

**GENERAL PERSPECTIVES OF POLIO
(PLENARY SESSION)**

WEDNESDAY AUGUST 31, 2011 AT 10.40–12.00

Summary 1

PROGRESS OF THE ERADICATION OF POLIO FROM WHO'S PERSPECTIVE

Rebecca Martin

World Health Organization

No abstract available.

Summary 2

THE STORY BEHIND THE POLIO ERADICATION CAMPAIGN

Peter Bundgaard, Orthodontist, Representative Rotary

Platanvej 31, DK-8680 Ry, Denmark

The speech gives a historical insight in the background for Rotary International's decision to engage in a worldwide project with the purpose of eradicating polio worldwide. The first step was Rotary's decision to eradicate polio in the Philippines, where this disease was very widespread. The next step was working with WHO, UNICEF and CDC, which showed their interest in the project after Rotary's success in the Philippines. They together made a plan to eradicate polio globally.

We found 3 types of poliovirus. Type 2 has not been detected since 1999 and must be considered eradicated. The vaccination campaign started with a trivalent vaccine active against all 3 types of poliovirus, but after elimination of type 2, a bivalent vaccine was developed and since then a monovalent vaccine active to virus type 1 or 3 has been developed. These vaccines have been used with great success.

One of the major problems associated with vaccination is that the vaccine is active only when it is below 8 degrees Celsius. Is it hotter, it becomes inactive and must be discarded. Therefore the "cold chain" is the crucial and often the large problem. The vaccine is used in very small drip bottles and transported in small insulated carrying bags up to the places where it should be used.

To date more than 2 billion children have been vaccinated, which means that more than 8 million cases of polio in children and 250,000 fewer deaths among children and adolescents has been prevented.

So far 3 of 6 WHO regions have been declared polio free. These are Americas Region in 1994, Western Pacific Region in 2000 and the European Region in 2002.

In all countries organizes WHO, UNICEF in corporation with local authority's implementation of vaccination often through the establishment of "National immunization days". In India in December 2002 154 million children were vaccinated in one day. A such large number of vaccinations can only take place with a great effort from both voluntary bodies and organizations.

The success is made up, but make clear that a positive outcome will require the continued donations from various quarters. The project has reduced the number of polio cases with 99.9%, but it is not finished until we reach 100% – and the final steps are the hardest and the most expensive.

It sets the annual savings once the project is fully implemented and the exploitation of the vast network of highly specialized laboratories that are built over time.

Summary 3

POST-POLIO SYNDROME, OVERVIEW OF CURRENT KNOWLEDGE

Frans Nollet, MD, PhD

Academic Medical Centre, Department of Rehabilitation, Amsterdam, The Netherlands

E-mail: f.nollet@amc.uva.nl

Post-polio syndrome (PPS) is the late decline in muscle function after many years of stability following the recovery of acute poliomyelitis. Although PPS has been anecdotally reported in the medical literature since the late 19th century, it was only in the early 1980s that PPS became recognized as a frequently occurring late consequence of polio when large numbers of people who had caught polio 30–40 years earlier during the large epidemics started to deteriorate in muscle function.

The diagnostic criteria that are now generally accepted are those as formulated in a consensus meeting by the March of Dimes in 2000. It must be emphasized that the diagnosis of PPS is made by exclusion, and other causes that may explain symptoms must have been ruled out.

The prevalence of PPS in polio survivors is estimated between 40 and 60%. From longitudinal studies, the decline in muscle strength is estimated at approximately 2% per year. More severe paresis has been reported as a prognostic factor for the decline in physical functioning.

The cause of PPS is not known. The most widely accepted hypothesis is that motor neurons in the spinal cord age prematurely due to the high metabolic demands and lose their ability to maintain the large motor units that were formed in the recovery phase after the acute polio. In recent years, it has been suggested that an inflammatory process might underlie PPS based on findings of raised concentrations of cytokines in the cerebrospinal fluid.

No pharmacological therapies sufficiently stop the decline in muscle function in people with PPS. Intravenous immunoglobulins have shown varying results and require further study. Rehabilitation interventions, such as physical training and lifestyle adaptations by behaviour modification, are commonly applied to reduce symptoms and preserve functioning. Physical therapy aims to reduce symptoms of overuse of weakened muscles, to limit the disuse of non-affected muscles, and to improve cardiorespiratory condition. Physical overload in daily life must also be reduced. This might require changes in activity pattern and the use of mobility assistive devices and home adaptations.

Key-points:

- The cause of PPS requires further study.
- The effectiveness of intravenous immunoglobulins needs further study.
- Randomised controlled trials of rehabilitation interventions are needed to show the effectiveness of multidisciplinary symptomatic treatment.

**INTERNATIONAL NETWORKING
(SESSION PRIMARILY FOR POLIO SURVIVORS)**

WEDNESDAY AUGUST 31, 2011 AT 13.00–14.30

Summary 4

**IMPROVING WORLDWIDE NETWORKING TO
IMPROVE THE LIVES OF ALL SURVIVORS**

Joan L. Headley, MS, Executive Director

*Post-Polio Health International, Saint Louis, Missouri,
USA. Info: post-polio.org; polioplace.org; ventusers.org.
E-mail: director@post-polio.org*

A network is composed of independent parts working together as an interdependent whole. In a network, people who are confronted with a common need realize there is something they do not like and go about creating something they do like. In a network, there is nothing to be won; there are only problems to be solved; problems that are solved by the personal contributions of many. Networks succeed because all individuals are valued for their contribution at every level. Recognizing that all tasks are important, networks deliberately create a decentralized pattern with many people accountable for the work.

Polio-focused organizations propelled the development of the injectable and oral vaccines in the late '50s and early '60s and promised a future without polio. Some dedicated their missions to the survivors of polio and evolved as their needs changed. The organizations were ready to step in when survivors reported the late effects of polio in the late 1970s.

The need for post-polio information coincided with the acceptance and explosion of self-help groups, consequently, polio survivors started numerous post-polio support groups and some are active today.

In 2011, the number of polio survivors worldwide continues to decrease. A reasonable estimate based on limited data is 0.171% of the current world population. The percentage of survivors in the US is about 0.25%.

What is the role of post-polio organizations as the number of survivors declines, as the needs of aging survivors increase, and as younger survivors experience problems in other countries, in some of which daily life is a struggle for all citizens?

Goal: Improving worldwide networking to improve the lives of all survivors.

Challenge 1: Clarifying the problem. New condition? Natural course of polio? Both? Unknown? Country dependent? Health system dependent?

Challenge 2: Finding the solution. Research? Health professionals? Polio survivor organizations? Individual survivors? All?

Challenge 3: Maintaining interest. Public? Policy makers? Researchers? Health professionals? Polio survivors?

Challenge 4: Expanding the Umbrella. Why? Who? How?

A network offers an opportunity for independent parts to work together as an interdependent whole. It offers an opportunity for speaking out, for cooperation, and as history can document, for success.

Reference:

Joan L. Headley, *Philosophy of Networking*, Revised March 2006.

**PATHOPHYSIOLOGY, PHARMACOLOGICAL RESEARCH AND TREATMENT
(SESSION PRIMARILY FOR POLIO SURVIVORS)**

WEDNESDAY AUGUST 31, 2011 AT 15.00–16.30

Summary 5

**PATHOGENESIS OF THE POST-POLIO
SYNDROME AND PERSISTENCE OF POLIOVIRUS
GENOMES IN POLIO SURVIVORS**

Antonio Toniolo, MD

*Institute of Microbiology, University of Insubria Medical
School, Varese, Italy*

Introduction: Infection by polioviruses (PVs) is limited to humans and certain primates. For entering into cells, viruses need to bind to molecules present in the cellular membrane that are called “virus receptors”. Virus binding is promoted by spatial matching between the external surface of the virus particle and its receptor (as it happens for a key and its lock). Once bound to the surface, the virus enters the cells and starts replicating. This process is called “virus infection of the cell”. It ends up by damaging the cell and producing more viruses. The receptor for PVs is called the CD155 molecule. CD155 is expressed in only a few cells of the body. Among them, the intestinal epithelium, cells of the lymphatic tissue, and cells of the Central Nervous System. The most important targets are the spinal motor neurons, whose function is to innervate voluntary muscles. Since PV infection kills these cells (and since motor neurons cannot be substituted through cell regeneration) paralytic lesions remain largely irreversible. These notions can explain the “pathogenesis” and clinical manifestations of paralytic polio.

In contrast, the origin of the post-polio syndrome (PPS) is unclear. Different factors have been blamed for: the aging process, the degeneration of the enlarged residual motor neurons that are proper of polio, and chronic inflammation. It has been proposed (but not proven) that the persistence of mutated PVs may cause the progressive neuromuscular damage seen in PPS.

Aims and results: We have investigated this hypothesis in 66 polio survivors diagnosed with PPS. As controls, family members of PPS patients (spouses, daughters, sons) and healthy blood donors were used. Virology studies showed that residual “genome fragments” of PVs (i.e., incomplete viruses) were present in over three quarters of PPS patients. Using the same methods, these “incomplete viruses” were not present in blood donors and family members. This finding demonstrates that there is no transmission of these “incomplete viruses” within the families of PPS patients. Through other experiments we also showed that the “incomplete viruses” still maintain some biologic activities, among which the capacity of inducing inflammation.

Conclusions: Small amounts of incomplete PVs can be detected in PPS patients, but are absent in their family members and in blood donors. Since the residual PV activity might be associated with inflammation and neuromuscular damage, we are working to find out treatments capable of suppressing the possible pathogenic effects of incomplete PVs (immunoglobulins, antiviral drugs). We thank Post-Polio Health International (St. Louis, MO) and Regione Lombardia (Milan, Italy) for financial support.

Summary 6

RESEARCH METHODOLOGY

Fieke S. Koopman, MD; Merel Brehm, PhD; Anita Beelen, PhD; Frans Nollet, MD, PhD

*Department of Rehabilitation, University of Amsterdam,
Academic Medical Center, The Netherlands*

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To obtain reliable research results, it is important that scientific studies meet certain criteria. One of the most important requirements is the inclusion of a control group in a study, in order to compare the results of a certain treatment in a group of patients with the results in a group of patients that did not receive the treatment. Furthermore, the study should (preferably) be conducted ‘blinded’, and the assignment of patients to treatment or no treatment should be random. In this way, a so-called placebo effect can be ruled out. However, there are many more methodological aspects that can (unintentionally) influence the quality and outcome of a study.

With regard to the treatment of post-polio syndrome (PPS), many scientific studies have been conducted. Depending on the methodological quality, these studies differ in the way they are being valued. To obtain a good overview and quality appreciation of all studies on treatment of PPS, we conducted a systematic review. The results of such a review can help health care practitioners, policy-makers, and patients in making well-informed decisions regarding treatment. In our review, the quality of all published studies on the treatment of PPS was assessed, and only the results from the studies that met certain pre-specified quality criteria were further evaluated and summarised. The results showed that a large number of studies could not be included in the review, because they did not meet the pre-specified quality criteria. The quality of the evidence for the treatments that could be further evaluated varied from very low to high. Unlike the large amount of studies performed on this topic, it was not possible to draw definite conclusions on the effectiveness of treatment for PPS.

Results from the review are published as Koopman FS, et al. Treatment for post-polio syndrome. Cochrane Database of Systematic Reviews 2011, Issue 2. Art. No.: CD007818.

Key points:

- To value the conclusions of a scientific study, the methodological quality needs to be taken into account.
- A systematic review is a powerful tool to provide a quality appreciation of carefully selected studies on a specific topic.
- A recent systematic review on treatment for PPS concluded that no definite conclusions can be drawn on the effectiveness of treatment for PPS.
- Future high-quality therapeutical studies are needed to find effective treatment for PPS.

Summary 7**PHARMACOLOGICAL TREATMENT FOR POST-POLIO SYNDROME AND MEDICAL PRECAUTIONS FOR POLIO SURVIVORS****Kristian Borg, MD, PhD***Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institutet Danderyds Hospital, Stockholm, Sweden*

The pharmacological treatment in post-polio patients (PPS) is often symptomatic and may be directed against symptoms of concomitant disorders. One must take into consideration side-effects that may be deleterious for PPS patients leading to for example increased breathing difficulties and decreased muscle power.

Different pharmacological agents have been directed against specific symptoms of PPS. The number of patients included in the studies has been low and there has often been a lack of controls making the result inconclusive. However, during recent years several randomized controlled trials (RCT) have been performed.

Improvement of walking was reported in a study of treatment with pyridostigmin. In another study, however, no effect of pyridostigmin was found. No difference was detected between co-enzyme Q-10 and placebo in PPS performing muscle training. Two different studies showed that Modafinil did not have any effect on PPS fatigue. Data from a study of Lamotrigine have shown promising results on pain, fatigue and quality of life. Intravenous immunoglobulin have been tested with the background of an inflammatory process in the central nervous system. Effects on muscle strength, pain, physical activity and quality of life were described.

In summary it is of importance to perform controlled studies of pharmacological treatment in PPS patients in order to increase function and activity. A special concern in PPS patients is the risk of developing serious side-effects.

Summary 8**PERSONAL EXPERIENCE WITH IMMUNOGLOBULIN TREATMENT****Esther Boserup, Polio survivor***E-mail: esther@boserup.info*

In 1948, when I was 5 years old, I had polio followed by paralysis of parts of the muscles in my feet, legs and lower back. From 1949 until 1976 I had rehabilitation and several operations of legs and feet, and from 1982 and on I have been treated at the PTU Rehabilitation center in Copenhagen.

I got married, had two children, and worked full time for 32 years. When I was in my late forties it became increasingly difficult for me to mount stairs, to walk more than a few meters without a walking stick and even to ride a bicycle.

In my fifties I started to feel increasingly tired, new weaknesses developed, my walking distance decreased dramatically and diffuse pains occurred. Along with that I developed weakness in parts of my muscles which had not previously been affected. I developed arthrosis of both hips and was diagnosed with post-polio syndrome in 2000.

From 1999 to 2003 I had four big operations (hip replacement, hysterectomy and mastectomy) and had to retire from my job as an editor. September 2009 I was treated with 90 g immunoglobulin intravenously 4 h a day for 3 days at the Danderyd Center for PPS, Stockholm. I experienced a considerable effect from the treatment and had no side effects.

Mental and physical tiredness decreased considerably, the heavy load of "fog" in my head decreased, pain ceased and muscles became stronger and more susceptible to training. My ability to focus and concentrate increased dramatically. I was able to sleep through the night. Sadness, lack of concentration, bad memory, feeling of inadequacy, was altered to energy and urge for action that involved physical movement. I regained my spirit and my positive outlook on life. It was a great experience!

I went to Stockholm anticipating that the treatment could suspend the negative post-polio development for a while. But it did a lot more than that – it improved my general condition and improved my quality of life dramatically. The very outstanding effect started gradually to deteriorate after 10 to 12 months. In December 2010 I was prescribed a second treatment with immunoglobulin in Stockholm, which was supposed to be given one year from the first treatment. But when writing this (April 2011) treatment of the Danish PPS patients in Stockholm has been cancelled. And I am back where I started.

**PATHOPHYSIOLOGY, PHARMACOLOGICAL RESEARCH AND TREATMENT
(SESSION PRIMARILY FOR HEALTH CARE PROFESSIONALS)**

THIS SESSION IS SPONSORED BY GRIFOLS

WEDNESDAY AUGUST 31, 2011 AT 13.00–14.30

Summary 9

PATHOPHYSIOLOGY OF THE POST-POLIO SYNDROME AND PERSISTENCE OF POLIOVIRUS GENOMES IN POLIO SURVIVORS

Andreina Baj¹; Giuseppe Maccari¹; Giorgio Bono²; Oscar Diaz-Horta¹; Antonio Toniolo¹

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Introduction: The natural transmission of polioviruses (PVs) is restricted to humans and certain primate species. PVs use the human poliovirus receptor (CD155) for infecting cells. CD155 is expressed in the intestinal and follicle-associated epithelium, M cells, lymphoid cells of germinal centers, spinal motor neurons of anterior horns (the virus' main targets), cells of intermediate gray ganglia, posterior horn and dorsal root ganglia. In paralytic polio, lesions can also be found in the reticular formation, vestibular nuclei, the cerebellar vermis, deep cerebellar nuclei, the pre-central gyrus of the motor cortex. Since motor neurons that are killed by PV infection cannot be substituted through cell regeneration, paralytic lesions remain largely irreversible. The above notions suffice to explain the pathogenesis and clinical manifestations of paralytic polio.

In contrast, the origin of the post-polio syndrome (PPS) is poorly understood. Different factors may account for the slow and progressive neuromuscular damage occurring in these patients: aging, the slow distal degeneration of the enlarged motor units proper of polio, chronic inflammatory damage of unknown origin. The hypothesis of a low-level chronic PV infection causing progressive neuromuscular damage has been formulated, but not proven.

Aims, methods and results: The latter hypothesis has been investigated in 66 polio survivors who developed PPS forty or more years after the acute attack. Cell culture and genomic methods showed that low-level infectivity and PV genome fragments could be detected in 55/66 (84,6%) PPS patients. Specimens included: cerebrospinal fluid, peripheral blood leukocytes, cells from duodenal mucosa, skeletal muscle, peripheral nerve. By the same methods, PV genome fragments were detected in only 2/61 adult controls (blood donors and family members of PPS patients). Most cases were associated with PV type 1 (70%), some with PV-2 and PV-3 (16% and 8%, respectively). That residual virus activity remained present in PPS patients was confirmed by two findings: a) epithelial cell lines exposed to samples of

PPS patients produced PV-coded proteins, and b) the latter "infected" cells produced enhanced amounts of inflammatory cytokines.

Conclusions: Small amounts of PV infectivity and associated inflammatory activity can be detected in PPS patients, but absent in healthy controls and in family members of patients. Thus, in polio survivors, the persistence of residual polioviral activity can be associated with chronic inflammation. We are working to find out immunologic/chemotherapeutic treatments capable of hindering the pathogenic effect of the residual PV activity.

Acknowledgments: This work supported by Post-Polio Health International (St. Louis, MO) and Regione Lombardia (Milan, IT).

Summary 10

POST-POLIO SYNDROME – IMMUNE MODULATION AND A POTENTIAL BIOMARKER

Kristian Borg, MD, PhD

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Late effects of poliomyelitis or the post-polio syndrome (PPS) consist of new or increased symptoms long after the acute infection. The most common symptoms are increasing or new weakness, fatigue and pain. Data from neurophysiological studies suggest that motor symptoms of PPS are due to an ongoing uncompensated denervation process. The background to the denervation is unknown. However, several hypotheses including overstress and/or overuse of remaining motor units, ageing, persistent polio virus and immunological factors have been presented. An intrathecal and peripheral inflammatory process as well as other signs of activation of the immune system have been reported, and immune modulation have shown promising results on molecular as well as clinical level and may be a therapeutic option. Furthermore, in a proteomic study a specific pattern with alteration of three proteins has been demonstrated. The three proteins are known to be involved in neuroinflammation and neurodegeneration and may be potential biomarkers. A biomarker for PPS is needed in order to monitor pharmacological as well as other rehabilitation interventions. The challenge today is to further clarify the basic pathophysiology of PPS and on the basis of this develop strategies for medical as well as rehabilitation interventions.

Summary 11**TREATMENT FOR POST-POLIO SYNDROME: RESULTS FROM A COCHRANE REVIEW**

Fieke S. Koopman, MD; Kimi Uegaki, PhD; Nils Erik Gilhus, MD, PhD; Anita Beelen, PhD; Marianne de Visser, MD, PhD; Frans Nollet, MD, PhD

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Introduction: In the past, many scientific studies on the treatment of post-polio syndrome (PPS) have been conducted, and new results from research on this topic continues to appear regularly. These include both studies on pharmacological treatment and rehabilitation management. Extensive evaluation of existing evidence for the effectiveness of these interventions has been done by the European Federation of Neurological Societies (EFNS) task force. However, no systematic review on this topic has been performed. Therefore, we systematically reviewed the effects of any treatment for PPS, compared to placebo, usual care or no treatment.

Methods: We searched the most commonly used databases (from inception to September 2010) for randomized and quasi-randomized controlled trials of any form of 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. Two investigators independently selected eligible studies, assessed the methodological quality of the studies and extracted data.

Results: Twelve studies were included in this review. There is moderate quality evidence that intravenous immunoglobulin (IVIG) has no beneficial effect on activity limitations, and there is inconsistency in the evidence for effectiveness on muscle strength and pain. Results of one trial provide very low quality evidence that lamotrigine might be effective in reducing pain and fatigue, resulting in fewer activity limitations. Data from two single trials suggest that muscle strengthening of thumb muscles (very low quality evidence) and static magnetic fields (moderate quality evidence) are beneficial for improving muscle strength and pain, respectively, with unknown effects on activity limitations. Finally, there is evidence varying from very low quality to high quality that modafinil, pyridostigmine, amantadine, prednisone and rehabilitation in a warm or cold climate are not beneficial in PPS.

Key points:

- This review indicates that IVIG, lamotrigine, muscle strengthening exercises, and static magnetic fields may be beneficial in treating symptoms of PPS.
- However, due to insufficient good quality data and lack of randomized studies, it is impossible to draw definite conclusions on the effectiveness of interventions for PPS.
- Future research should focus on novel trials of interventions in PPS to establish evidence on the effect of treatment, which will improve patient care.

Summary 12**REVISED EFNS GUIDELINES FOR DIAGNOSIS AND MANAGEMENT OF POST-POLIO SYNDROME**

Elisabeth Farbu, MD, PhD; Nils Erik Gilhus, MD, PhD; Michael P. Barnes, MD, PhD; Kristian Borg, MD, PhD; Marianne de Visser, MD, PhD; Robin Howard, MD, PhD; Frans Nollet, MD, PhD; Josef Opara, MD, PhD; Erik Stålberg, MD, PhD

Department of Neurology, Stavanger University Hospital, Stavanger, Norway

Some years ago, the European Federation of Neurological Societies (EFNS) decided to try to bring together peer-reviewed guidelines for the treatment and management of neurological disorders. These guidelines should be based on evidence, and where evidence was not available, by consensus of experts from different European countries.

The EFNS task force on post-polio syndrome consists of members from Norway, UK, Sweden, The Netherlands, and Poland, involving different medical specialties and a patient representative. The first guideline document was published in European Journal of Neurology in 2006 as well as in the first edition of European Handbook of Neurological Management. The revised guideline which is presented here was published in the second edition of European Handbook of Neurological Management 2010.

Medline via PubMed, EMBASE, ISI and Cochrane databases were searched with time limits 1966–2009, and the task force reached consensus after discussion by e-mail.

We recommend that The March of Dimes criteria for PPS should be used.

For specific treatment regimens we found that:

- No therapeutic effects have been reported for pyridostigmine, steroids, amantadine, modafinil, and Coenzyme Q10 (Level A).
- Supervised muscular training can prevent further decline of muscle strength in slightly or moderate weak muscle groups, and can reduce muscular fatigue, muscle weakness, and pain. Precautions should be taken to avoid muscular overuse (Level B).
- There are no data evaluating the effect of muscular training in patients with severe weakness (Level B).
- Training in warm climate and non-swimming water exercise are particularly useful (Level B).
- Respiratory muscle training and early recognition of respiratory involvement with introduction of non-invasive ventilatory aids can alleviate respiratory symptoms (Level C).
- Group training, regular follow-ups and patient education are useful for the patients' well-being (Level C).
- Lightweight carbon orthoses can be more proper than metal orthoses (Level C).
- Weight loss (if adipose) and introduction of properly fitted assistive devices is helpful (Good practice points).
- More studies on IvIg and prospective follow-up studies evaluating muscle strength and the natural course of PPS are welcomed.

PATIENT ASSESSMENT
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)

WEDNESDAY AUGUST 31, 2011 AT 15.00–16.30

Summary 13**POST-POLIO SYNDROME: DIAGNOSTIC TOOLS**

**Laura Bertolasi, MD^{1,2}; Salvatore Monaco, MD¹;
Gianluigi Zanusso, MD¹; Elisa Dall’Ora, MD¹;
Fabiana Pimazzoni, MD¹; Monica Ferlisi, MD¹;
Michele Acler, MD¹; Bruno Danzi, MD²;
Millo Martini, MD²**

¹Department of Neurosciences, University of Verona, and

²Division of Rehabilitation Medicine, National Centre for polio survivors, Hospital of Malcesine, Italy

Post-polio syndrome (PPS) occurs in 20–85% of patients with prior acute anterior poliomyelitis (AAP) and represents an important cause of motor neurological disability worldwide. Firstly reported by Raymond in 1875, PPS is a complex chronic condition, characterized by progressive amyotrophy in previously unaffected muscles, or by worsening of the atrophy in muscles previously involved. Additional signs are generalized fatigue, muscle and joint pain, cramps and fasciculations, cold intolerance, and sleep disturbances. As yet, the pathophysiology of PPS is not clear, but the finding of increased level of inflammatory markers in cerebrospinal fluid (CSF) suggests the involvement of immunological mechanisms. The pathogenic and diagnostic role of specific proteins found in the CSF of patients with PPS is still obscure. Whatever the mechanisms, the European Federation of Neurological Society recommends the following diagnostic criteria (March of Dimes, 2000):

1. prior AAP (by clinical history, focal muscle atrophy and weakness, denervation on electromyography);
2. functional recovery after AAP followed by a period of stable neurological condition (>15 years);
3. gradual or sudden onset of progressive and persistent muscle weakness/fatigue, either focal or generalized with muscle atrophy or muscle and joint pain;
4. symptoms lasting at least a year;
5. exclusion of other medical, orthopedic or neurological conditions.

Electromyography has an important diagnostic role, either in documenting previous motor unit loss, or in excluding other neurologic disorders mimicking PPS. In this setting, radiological investigations also contribute in excluding other comorbidities or poliomyelitis-associated disorders. To date, no specific diagnostic tests are available for PPS, hence the characterization of biomarkers reflecting disease activity and pathogenic processes in PPS would make possible the tailoring of specific treatments.

Summary 14**ELECTRODIAGNOSTIC STUDIES: WHAT, WHEN, WHY, WHY NOT?**

Arzu Yagiz On, MD

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Electrodiagnostic studies that can be performed in the patients with poliomyelitis mainly include needle electromyography (EMG), nerve conduction studies (NCS), motor unit number estimation (MUNE) and macro EMG.

Needle EMG is a test that analyses the motor unit potentials (MUPs) in a muscle, by inserting a very small diameter needle into a muscle. In the patients who have had paralytic polio, a needle EMG study will detect evidence of chronic denervation and ongoing reinnervation in the affected muscles. Denervation and loss of motor units are reflected by decreased recruitment, whereas increased motor unit size due to reinnervation is reflected by increased amplitude or duration of the MUPs in needle EMG. Subclinical motor neuron involvement of certain muscle groups may be found in needle EMG of the muscles that were considered to be originally unaffected by poliomyelitis.

Macro EMG is a relatively new technique for the study of the motor unit. Since this technique gives information about the whole motor unit, it reflects size and number of the muscle fibers within a motor unit. Thus, in the patients with a history of poliomyelitis, macro MUP amplitudes are increased.

MUNE is a technique that gives an estimation of motor unit number in a given muscle. MUNE has been shown to be reduced not only in the affected muscles, but also in those that thought to be originally unaffected by polio virus.

Electrodiagnostic studies are of no value in diagnosing PPS. Then under what circumstances would performing these studies be justified on a patient with a history of poliomyelitis or on a patient with symptoms suggestive of PPS? The major role of electrodiagnostic studies is to confirm lower motor neuron involvement compatible with previous paralytic polio and to determine degree of motor neuron loss. EMG will also be useful to detect the presence of sub-clinically involved muscles. In the patients with symptoms suggestive of PPS, EMG would also be helpful to evaluate concomitant disorders and to identify or rule out other conditions that may cause the similar symptoms of PPS. Another situation where an EMG will be appropriate is when a patient has been misdiagnosed with poliomyelitis. In this situation, EMG will be helpful in ruling out poliomyelitis and in determining the presence of another disorder.

Summary 15**DIFFERENTIAL DIAGNOSIS FOR POST-POLIO SYNDROME****Marianne de Visser, MD***Academic Medical Centre, Department of Neurology, Amsterdam, The Netherlands. E-mail: m.devisser@amc.nl*

A diagnosis of post-polio syndrome (PPS) includes 1) previous diagnosis of paralytic polio, 2) at least 10 years of functional stability, 3) new or increased muscle weakness and fatigue and often pain, 4) no other medical or neurologic conditions explaining new symptoms. Therefore, if a former polio patient presents with symptoms typical of PPS it is important to first exclude other conditions which could be producing these symptoms. The history taking and neurological examination will reveal whether there is a credible history of polio and if there are sequelae. If pain is a prominent complaint one should consider radiculopathies or entrapment neuropathies in particular if crutches are used which may affect the median or ulnar nerve. In those cases electromyography and imaging of the spine can be of added value. Routine laboratory tests are usually not required.

In particular it is important to consider a differential diagnosis if progression of muscle weakness is faster than is usually the case in PPS (motor neuron disease or any other neuromuscular disorder like sporadic inclusion body myositis), if there is fatigue and weakness without clear polio sequelae (e.g., hypothyroidism) or if there are sensory symptoms and signs in a PPS-patient (spinal cord disorder or polyneuropathy). If a patient presents with bulbar dysfunction or respiratory insufficiency (shortness of breath or laryngospasm) myasthenia gravis or motor neuron disease should be ruled out.

Patients with former polio may also acquire other neurological disorders. We will discuss several cases, i.e., syringomyelia, idiopathic plexus brachialis neuropathy, cervical myelopathy due to a degenerative spinal stenosis, muscle amyloidosis in patients who were known to have PPS. However, we also had referrals of patients diagnosed as inflammatory demyelinating neuropathy or hereditary spinal muscular atrophy and were proven to have PPS, or conversely a patient who was diagnosed as PPS and had hereditary neuropathy.

It is recommended to perform muscle imaging routinely because it may be helpful to assess the extent of muscle involvement. All too often patients report that only one limb was affected during the acute infection and that they have developed weakness in their 'good' leg. Muscle imaging then may reveal replacement of fat in the supposedly unaffected limb indicating that there had been previous involvement which had gone unnoticed.

Key points:

- Patients with previous polio may also acquire disorders mimicking PPS.
- PPS patients may develop other neurological disorders causing progressive symptoms erroneously attributed to PPS.

Summary 16**REHABILITATION ASSESSMENT****Frans Nollet, MD, PhD***Academic Medical Centre, Department of Rehabilitation, Amsterdam, The Netherlands
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The diagnosis of post-polio syndrome (PPS) is made after the exclusion of other medical conditions explaining the new symptoms. Except neurological symptoms, secondary disorders of the locomotory system are quite common and may cause symptoms. Since the acute polio usually occurred at young age, most polio survivors have developed skeletal abnormalities during growth such as shortening, axial and rotational deviations of shaft bones, and hypermobile, hypoplastic joints. With age joints laxity may increase, and osteo-arthritis may arise in affected and unaffected legs. Also in the upper extremities degenerative disorders are quite common due to prolonged overuse.

Secondary disorders of joints, ligaments and tendons, may hamper diagnosing PPS. For instance it can be impossible to distinguish whether weakness is due to a decline in muscle function or secondary to symptomatic osteo-arthritis of the joint on which the muscle acts. Overuse of (paretic) muscles may cause symptoms of pain and cramps but do not necessarily imply that these muscles are symptomatic due to PPS. It may well be that the complaints are due to overload of muscles that compensate for other, weakened muscles during physical activities.

Since multidisciplinary rehabilitation aims to preserve functioning, the assessment of the patient focuses on the execution of activities and in this light impairments are valued. For instance, the strength of a paretic muscle is judged in view of the strength requirements to execute a task such as safe and prolonged walking. Therefore, a functional assessment of activities, such as walking, standing, transferring between bodily positions, walking stairs is necessary to gain insight in the loading of muscles and joints during these tasks. Attention should not only be given to affected body parts but also to compensatory use of less or unaffected body parts. In patients with severe polio residuals, the observation of daily activities is warranted to understand symptoms which result from overload. Clinical gait analysis may be particular useful to objectify overuse complaints due to gait abnormalities and energy cost measurements can objectify the increased energetic demands of walking due to reduced movement efficiency. These objective tools furthermore allow the evaluation of the effects of interventions, such as braces.

Key points:

- Functional assessment is needed to understand the symptoms of PPS which result from overuse during the execution of physical activities.
- Multidisciplinary assessment of daily functioning is the fundament to an individually tailored therapy rehabilitation program.

FREE PAPERS

THURSDAY SEPTEMBER 1, 2011 AT 9.00–10.00

Summary 17

AUSTRALIA'S POLIO HEALTH AND WELLNESS RETREAT: IMPROVEMENTS IN SELF-MANAGEMENT STRATEGIES FOR PEOPLE LIVING WITH THE LATE EFFECTS OF POLIO (LEOP) FOLLOWING 3 DAY RESIDENTIAL PROGRAM

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In April 2010, Polio Australia conducted Australia's first three day "Polio Health and Wellness Retreat" in New South Wales. The purpose of the Health and Wellness Retreat was to provide a holistic approach to managing the late effects of polio (LEOP) and finding life balance. Each day focussed on a different aspect of health and wellness: Body, Mind and Spirit. This Retreat model was adapted from Polio Health International's Post-Polio Wellness Retreat held in Warm Springs, USA in 2009. It is now being used as a chronic condition self management technique in Polio Australia activities, with a second Retreat run in Victoria in April 2011 and a third scheduled for Queensland in 2012.

As there were a number of partners/carers participating, there were also scheduled and informal opportunities for them to meet and discuss their own specific concerns.

According to the sample evaluation comment below, this Retreat has 'changed people's lives':

"Thanks for all you put into the retreat. For me it was a life-changing experience! It seemed to offer everything we needed: great plenary sessions, excellent small group discussions and one-to-one opportunities with professionals, and the chance to share all these experiences with one's partner. Beyond that, there was the informal chance to make connections and share experiences with other polio survivors. Congratulations to everyone involved. I've already made three important follow-up appointments...."

In order to verify changes in the participant's self-management practices as a result of attending the Retreats, people completed a follow-up questionnaire reporting on their progress after a 6 month period.

It is intended that funding be sought so that Polio Health and Wellness Retreats can be facilitated across Australia as a key program component towards achieving Polio Australia's vision of ensuring that all polio survivors have access to adequate support and information together with comprehensive, consistent health care from a range of well-informed and educated professionals.

Summary 18

THE WARM EMBRACE OF PEER SUPPORT

Anne Shanahan, MA

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Peer support within the Post Polio Group Ireland was augmented over a 3-year period by establishing local groups consisting of Polio Survivors, their families and carers. These groups were set up throughout the country and were networked on a national basis.

Initially, local areas were identified where clusters of members could attend meetings with relative ease and be able to participate in a comfortable, non-threatening environment. In this safe space members were able to share their good and bad experiences without fear of judgment; to listen to each other; to support each other; to avail of information and to enjoy the social interaction. As the participants became more confident, energized, powerful and self-reliant they warmly embraced the freedom to come to terms with the constraints of their disabilities; to strive for better more fulfilled and happy lives and above all to support and encourage each other. In sum, all responded as thinking, reflective people with a great capacity for action and a hunger to help other Polio Survivors.

Peer support is also offered to members who are unable to attend group meetings by schemes for telephone support. This is provided by the members to the members on a one-to-one basis or by group conferencing.

The outcome of this national interactive network is recognition and understanding of the impact of post-polio syndrome on living standard, lifestyle and personal achievement potential. With recognition has come the possibility for solutions and mechanisms to surmount personal and societal limitations. Polio Survivors need good quality medical care all through life but they can do much for themselves to become more outgoing, confident and ultimately more fulfilled.

The warm embrace of peer support has provided a life enhancing outcome for many of our members as the difficulties they experience are shown to be often more social than medical in origin.

Summary 19**DISUSE OSTEOPOROSIS IN THE PATIENTS WITH POST-POLIO SYNDROME****Jülide Öncü, MD, Specialist on PMR***Sisli Etfal Hospital, Physical Medicine and Rehabilitation Clinic, Istanbul, Turkey*

Introduction: It is well known that removal of regular weight-bearing activity results in a loss of bone mineral. Although disuse osteoporosis has been reported in several neurological disorders such as spinal cord injury and stroke, it has not been investigated in the patients with poliomyelitis so far.

Aims: The aims of the study are to investigate bone mineral densities (BMDs) at multiple sites in the patients with poliomyelitis, and to compare the BMD of the hips on the affected and unaffected sides.

Methods and material: 30 ambulatory polio patients (15 men, 15 pre-menopausal women) with unilateral lower limb involvement were included. BMD of the lumbar spine and both hips including the area of femoral neck and greater trochanter were measured by dual-energy X-ray absorptiometry.

Results: BMDs of the femoral neck and the greater trochanter were significantly lower in the affected side comparing to those in the unaffected side. BMD reductions were more profound at the greater trochanter. Based on the T-score, none of the patients had osteoporosis at the lumbar spine. No statistically significant differences in BMDs were found between the men and women.

Conclusions: Disuse osteopenia and osteoporosis of the hips are very common at the affected side of the patients with poliomyelitis. Diagnostic and treatment strategies are needed for polio patients to prevent further decreases in BMD and reduce the risk of fractures.

Summary 20**RAMESH FERRIS CYCLE TO WALK POLIO ERADICATION, EDUCATION, REHABILITATION****Ramesh Ferris***Ramesh Ferris Polio Foundation, Whitehorse, Yukon, Canada. Info: www.rameshferris.com*

An 8 Billion US Dollar Global Investment towards polio eradication has been made as part of the world's largest public health initiative, The Global Polio Eradication Initiative, which commenced in 1988.

Members of Rotary International have contributed over 1 Billion US Dollars as part of its Rotary International PolioPlus Program which started in 1985. Rotary has been responsible for vaccinating over 2 Billion children and is committed to ensuring that the World achieves the status of a Polio Free World.

The World Health Organization predicts that an additional 10 million children will be paralyzed over the next 40 years if we choose to not continue the fight against polio.

In 1985 there were an estimated 400,000 cases of polio annually spread over 125 countries. In 2010 there were 975 cases worldwide and polio is now endemic in 4 countries; Pakistan, Afghanistan, India and Nigeria.

On April 12, 1955 Dr. Jonas Salk's Polio Vaccine was released!

25 years after, the world had better than a cure, it had prevention, Ramesh Ferris contracted polio in India where he was born.

In our world we have a culture of crawlers, polio survivors who do not have access to rehabilitative supports and rely on using cut up pieces of tires to pad their knees and hands to crawl around their communities. It is estimated that there are approximately 10–20 million polio survivors currently living around our world today, many of them are in need of rehabilitative aides and other post-polio related services.

In 2008 Canadian Polio Survivor Ramesh Ferris Hand-Cycled 7,140 km across Canada as part of a campaign he called Cycle to Walk to raise awareness and funds for polio eradication, education, and rehabilitation.

Many people in developed countries think that polio is a disease of the past. Parents are choosing not to have their children vaccinated against polio. 11 percent of Canadians have not received the polio vaccine, 8–10 percent of the American population have not received the polio vaccine. The Polio Vaccine does not cause autism and it is not a western ploy to sterilize young Muslim children.

**SYMPTOMS AND MANAGEMENT 1
(SESSION PRIMARILY FOR POLIO SURVIVORS)**

THURSDAY SEPTEMBER 1, 2011 AT 10.30–12.00

Summary 21

ORTHOPEDIC SURGERY IN POST-POLIO SURVIVORS

Anders Stenström, MD, PhD, Professor of Orthopaedics

Department of Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden

The problem of operating people with post-polio (now often between 50 and 80 years of age) has to do with weak muscles, paralysis, muscle atrophy and imbalance between extensor and flexor muscles and it puts high demands on postoperative rehabilitation and orthotic treatment.

Hip disease is a relatively common problem in people with post-polio due to overload, muscular stiffness, trochanteritis and arthrosis. Local cortisone injections may cure some of these diseases. There have been hesitations about operating hip arthrosis with total hip replacement due to the risk of luxation of the endoprosthesis because of the weak muscles but in our experience careful preoperative planning often including CT or MRI and postoperative rehabilitation shows successful outcome of total hip replacement in people with post-polio.

Regarding the knee there are no contraindications to perform arthroscopic surgery for meniscal and chondral lesions. In knee arthrosis total knee replacement using a stabilized knee endoprosthesis can sometimes be successfully performed. Performing high tibial osteotomy and unicompartmental endoprosthesis is contraindicated. Knee joints with hyperextension secondary to polio should preferably be treated with orthosis.

In the ankle joint athrodesis might be considered in severe medio-lateral instability. Most ankle and foot deformity as well as drop foot can successfully be treated with orthosis, insoles, shoes or boots.

Performing tendon transfers is as a rule contraindicated in people with post-polio.

Fractures, like for instance hip fractures, supracondylar femoral fractures, tibial condylar and tibial fractures, ankle- and foot fractures and luxations as well as fractures in the upper extremity, are treated surgically in the same way as in non post-polio people. Physiotherapy and plaster/orthosis are mandatory in the postoperative treatment.

In summary orthopaedic operations can successfully be performed on people with post-polio but on very strict indications and with special postoperative rehabilitation. Special orthosis can in many situations be a valuable solution as an alternative to operation.

Summary 22

ANESTHESIA ISSUES FOR POLIO SURVIVORS

Selma Harrison Calmes, MD, Clinical Professor of Anesthesiology (Retired)

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There is little data about how polio survivors actually do during anesthesia. Current recommendations are based on anatomic changes from the original disease, except in the area of muscle relaxant dose. Modern anesthesia is quite safe and, with a good preoperative evaluation and a cooperative team for postop care, every polio survivor can have needed surgery safely.

Every post-polio patient is different and needs to be evaluated well before surgery. This should start with pulmonary evaluation. Although not documented in the medical literature, postop pulmonary failure appears to be the greatest hazard from surgery, and those who needed iron lungs in their original disease appear to be at greatest risk. Sleep apnea patients and those with scoliosis are other high-risk groups for postop respiratory failure. Pulmonary function test, and perhaps arterial blood gas, are needed. Laryngeal and oropharynx dysfunction is common and should be evaluated if suspected, because of the risk of aspiration. Other medical diseases need to be evaluated and controlled.

An anesthesiologist should see the patient well before surgery. The anesthesia plan should be complete and should include a plan for aggressive postop pain management, usually with local anesthesia. There should be a plan for postop ventilation needs. The anesthetic requirements for the operation, especially the position needed, should be discussed ahead of time with the surgeon. Position is an important issue; not every polio patient can be placed in the more difficult surgical positions. If muscle relaxants are used, neuromuscular transmission should be monitored with a nerve stimulator. Half the usual dose is recommended. Complete reversal of the relaxants must be documented at the end of case, before attempting extubation. If the patient has sleep apnea, uses continuous positive airway pressure (CPAP) at home and can be extubated, they should be extubated to CPAP. (Anesthesia causes worsening of sleep apnea abnormalities.)

Regional anesthesia is suitable for post-polio patients and has been widely used, without documented worsening of existing neurologic damage. Portable ultrasound and other imaging techniques are helpful in placing blocks in patients with anatomic distortions from polio. Because postop pain is often a problem, regional techniques can be extended into the postop period to provide pain relief.

Patients should be closely observed for postop respiratory failure, especially those at greatest risk. Postop respiratory failure can be difficult to manage and should be done in an experienced intensive care unit.

Summary 23**RESPIRATION AND SLEEP****Michael Laub, MD, PhD, Dr Med Sc***Respiratory Centre East, Rigshospitalet, Copenhagen University Hospital, Copenhagen, Denmark*

The Scandinavian countries experienced several polio epidemics in the first half of the 19th century. Some hospitals in Scandinavia were at that time equipped with negative pressure (tank) ventilators that were used for polio patients with respiratory failure, mortality was, however, quite high. The Copenhagen polio epidemic in 1952 turned out to be exceptional by the very high attack rate, the severity of symptoms and the significance of the new therapeutic measures that were introduced. The epidemic in Copenhagen not only gave a lead to the concept of intensive care units all over the world, ushered in a renaissance in clinical respiratory physiology, it, furthermore, created a demand for mechanical positive pressure ventilators as well. The polio patients who did not recover sufficient ventilation following the acute infection made up the first 'users' on home mechanical ventilation (HMV).

During the decades after the polio epidemics patients with other diseases resulting in chronic respiratory insufficiency or hypoventilation rarely initiated HMV, but in the mid-late 1980s the number of patients on HMV, mainly with restrictive respiratory defects, started to increase markedly in many countries. This was caused by technical improvements of the equipment, first of all the possibility to apply non-invasive ventilation in a large scale, primarily via a nasal or full-face mask, and because of added attention from physicians as well as the patients on the option to implement HMV. Today home ventilation worldwide is provided in a large number of patients with a broad aetiological background. An European Commission-funded consensus identified 21.526 ventilator-dependent patients in 16 European countries. This was equal to an estimated prevalence of HMV in Europe of 6.6 per 100,000 people (2002 figures). Poliomyelitis has been eradicated in most western countries for several years. The late-onset respiratory sequelae present in patients with post-polio syndrome imply, however, that we still embark these patients on respiratory support.

Summary 24**SPEECH AND SWALLOWING****Svend Prytz, MD***Denmark*

No abstract available.

**SYMPTOMS AND MANAGEMENT 2
(PRIMARILY FOR POLIO SURVIVORS)**

THURSDAY SEPTEMBER 1, 2011 AT 13.00–14.30

Summary 25

FATIGUE – SYMPTOMS AND MANAGEMENT

Gunilla Östlund, PhD, Licenced psychologist
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Fatigue is a subjective phenomenon described as a negative feeling regarding ones feeling to perform physical and mental activities. It is a normal experience in healthy individuals after mental or physical work, and increasing age has been associated with increasing fatigue. Also physical fatigue increases with increasing age due to a loss of motor neurons. Fatigue can be divided into central fatigue, the central nervous system, and peripheral fatigue, due to affection of the peripheral nervous system and the muscles. It is also a common symptom in different concomitant disorders. In post-polio syndrome (PPS) patients fatigue is reported in up to 90%. Physical fatigue is considered to be the major problem, due to an decreasing compensatory process in surviving motor neurons. Sometimes, fatigue in PPS is described as a flue-like exhaustion, worsened by physical activity, low in the morning and increasing during the day. An inflammatory process in PPS may also play a role in the fatigue experience. Muscle and joint pain is together with fatigue one of the most common symptoms in PPS. Pain and fatigue often co-occur, and PPS patients with muscle pain had longer lasting general fatigue and higher fatigue severity. Other factors related to daytime tiredness and fatigue are sleep problems and sleep disordered breathing and mental health problems, especially depression can be associated with fatigue and increased fatigability. Fatigue together with high physical work demands, low social support and pain have been identified as barriers to full work participation. Fatigue in PPS can be managed in different ways. Making lifestyle changes like using energy conservation techniques is one. Using assistive devices is another. When respiratory insufficiency is present assisted ventilation may be necessary. Muscle weakness and muscle pain training in warm water seem to be helpful. Treatment with intravenous immunoglobulin is promising, but some questions needs to be answered, like identifying responders and non-responders.

Summary 26

PAIN IN POLIO SURVIVORS

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Professor in Rehabilitation Medicine**
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Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage.

Pain is always subjective. Each individual learns the application of the word through experiences related to injury in early life. Biologists recognize that those stimuli which cause pain are liable to damage tissue. Accordingly, pain is that experience we associate with actual or potential tissue damage. It is unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience.

So how is pain experienced and expressed of those with polio? One aspect to relate to is that according to those who have had polio, the acute period was painful. How does a child react when it has pain and learns that the adults do not or cannot lessen the pain. Training weak muscles is painful and giving in to pain reflects the results, therefore in the training sessions ignoring the pain is beneficial. How does this affect the perception of painful stimuli in the brain later on? Can it be that the "old polio pain" is not perceived in the same way as an acute myocardial infarct because the brain has been taught to ignore the polio pain. Many with polio experience pain. Many with pain seem to be active close to maximal capacity in daily life. This can be noted as inability to increase walking speed when asked to. What is the cause of the pain? Neuropathic or musculoskeletal? What triggers the pain? Hard work or rest? What reduces the pain? Rest or activity?

It seems as if pain is common in persons with polio. However, not much is known about the causes of pain nor the consequences and the treatment. There is a need for further research regarding this.

The opinions of those living with polio needs to be addressed. The involvement of persons living with polio in research is needed.

Summary 27**IMPACT OF COMORBIDITY, AGING AND LIFESTYLE-RELATED FACTORS IN POLIO SURVIVORS**

Irene Tersteeg, MD; Janneke Stolwijk, MD, PhD; Anita Beelen, PhD; Frans Nollet, MD, PhD

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When aging, many polio survivors encounter late-onset neuromuscular symptoms including new or increased muscle weakness and a decline in functioning. The rate of progression is generally slow. Prognostic factors for the rate of progression of muscle weakness have not been identified so far. For the decline in functioning, there is evidence that the extent of paresis negatively affect the course of functioning over time. Patients with more widespread paresis have a faster decline in functioning. In these patients small changes in muscle strength may have profound functional consequences since these patients lack spare muscle capacity and their ability to adapt with new functional solutions by using other muscles is limited. Next to the extent of paresis, comorbidity has been identified as a prognostic factor for functional decline. Polio patients have a slightly increased rate of comorbid diseases such as pulmonary, cardiovascular, gastrointestinal diseases, and diseases of the locomotive apparatus. Patients with more comorbid conditions have a lower level of functional independence, perceive their physical functioning to be poorer and have a faster decline in functioning compared to polio survivors without comorbidity. Age has been identified as a determinant of functional independence but not of perceived physical functioning, probably due to a psychosocial adjustment in ageing with physical limitations. Age has not been shown to be an independent factor that influences the decline in functioning over time.

Residuals from polio and new neuromuscular symptoms may lead to physical inactivity and excess body weight. Although scientific evidence for the impact of these lifestyle-related factors on the decline in functioning of polio survivors is limited, these factors are recognized as risk factors for cardiovascular diseases and as such, should be included in the treatment of polio survivors.

As comorbidity negatively affects the course of functioning in polio survivors, it should be recognized early by active screening and treated adequately. Education on controllable risk factors for comorbidity should be provided.

Key points:

- Physical functioning in polio survivors declines slowly and prognostic factors for a faster decline in functioning are extensive residual paresis and co-morbidity.
- Screening for and monitoring of comorbidity should be included in the management of post-polio patients.

Key point for further research:

- Uniformity in outcome measures on all levels of functioning (impairments, activities and participation) is crucial to obtain insight in the course of functioning over time and prognostic factors.

Summary 28**VOIDING AND BOWEL PROBLEMS**

Lise Kay, MD

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Introduction: The process of voiding and bowel movements are determined by a variety of factors such as social, cultural, upbringing, toilet access, physical ability, diuresis and of course nerve innervation and muscle strength in the pelvic region. Theoretically, these factors may have a special impact on polio survivors, as their disease has brought about consequences in many of these fields.

A Danish survey of polio survivors revealed that they had more voiding problems than the general population. No data have been published about bowel problems among polio survivors, but it has been shown that a reduction in functional ability is a predictive factor for bowel symptoms.

Voiding and bowel problems may hinder participation in social life and thereby be an obstacle to successful rehabilitation.

Aim: The aim of this contribution is to set focus on the issue and to give some guidelines on how to handle the problems. However, as with all other symptoms in PPS, other diseases should be eliminated before putting down PPS as the cause.

Voiding problems: A thorough anamnesis, physical investigation and a drinking/voiding chart should be done. This may show the way to alleviate problems by simple means such as adjusting drinking and voiding habits of facilitating access to the toilet.

Next step is to carry out an ultrasound to measure residual urine in order to discriminate between problems caused by retention and problems caused by bladder instability. The final step is to carry out a full urodynamic investigation, this should be carried out by a urologist who can initiate more complex treatments.

Bowel problems: Constipation can primary be treated by adequate balance of water and fiber content in the food, and by building up stable toilet habits. Massage of the anal region and sitting in a position with knees up close to the stomach may also facilitate bowel movement. Secondly, laxatives acting by keeping fluid inside the bowel can be used without restriction, while laxatives that push the peristaltic movements may theoretically overload the moving ability of the bowel and make things worse. Enemas can supplement oral laxatives. Ultimately, regular emptying by irrigation up high in the left side colon may relieve severe coprosthesis. This technique can be learned at hospital departments with special interest in the field, and can afterwards be carried out at home.

Key points:

- Voiding and bowel problems experienced by polio survivors can be relieved and if not by simple means patients should be referred to hospital departments with specialists.

**SYMPTOMS AND MANAGEMENT 3
(PRIMARILY FOR POLIO SURVIVORS)**

THURSDAY SEPTEMBER 1, 2011 AT 15.00–16.30

Summary 29**FALLS AMONG POLIO SURVIVORS**

Alice Bickerstaffe, MD; Anita Beelen, PhD; Frans Nollet, MD, PhD

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Falls are a clinically important, but underrated problem for polio survivors. There has been little research on the topic, despite the fact that an estimated 10–20 million people worldwide are living with the consequences of polio, many of whom suffer from a variety of symptoms that are known risk factors for falls in other patient groups. In particular they often have extensive asymmetrical muscle weakness, muscle and joint pain, and fatigue. All of which may contribute to balance problems and the occurrence of falls.

Studies of fall frequency among polio survivors have shown that 50–84% of polio survivors fall at least once a year. This yearly fall incidence is considerably higher than that in elderly people, where it is 32–42% for those over 75 years of age. Our recent questionnaire-based study among 305 polio survivors in the Netherlands confirmed previous findings, with 74% of participants falling at least once in the previous year and 60% at least twice. In addition, 16% of fallers described major injuries after a fall in the last year and 69% reported fear of falling. Both physical and psychological consequences of falls can have severe long-term effects. In older people fall-associated fractures are a significant source of morbidity, mortality and loss of independence while associated fear of falling and loss of confidence can result in unnecessary reduction of activities and social isolation. For this reason many fall prevention strategies have been developed for elderly people, with exercise therapies reducing fall rates up to 36%. Yet, while the fall incidence among polio survivors is much higher than in the elderly, no fall intervention has been developed for this population.

The high rate of falls and consequences thereof, merit the implementation of fall intervention strategies. To maximize effect they should target fall mechanisms specific to polio survivors. Previous research has shown that lower limb muscle weakness, fear of falling, loss of proprioception and complaints of problems maintaining balance are independently associated with balance problems, falls and recurrent falls among polio survivors. Measures tackling these issues should therefore be incorporated into any future fall intervention for polio survivors.

Key points:

- Falls are a clinically important problem for polio survivors, yet no therapy currently exists.

Key points for future research:

- Development of fall intervention strategies for polio survivors is crucial. These should target polio-specific risk factors at an individual and group level.

Summary 30**EXERCISING FOR POLIO SURVIVORS**

Deirdre Murray, BSc Physiotherapy, (PhD student)^{1,2}

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The American College of Sports Medicine recommends 20 to 60 min of moderate intensity aerobic exercise, 3–5 days per week for healthy adults, as well as strengthening exercise and flexibility exercise. Those with chronic conditions should be as physically active as their conditions allow.

A wide range of benefits of exercise have been identified, including prevention of heart disease, depression, obesity, stroke and diabetes. It is important that Polio Survivors can benefit as much as possible from these positive effects of exercise.

There are potential barriers to exercise for Polio Survivors, including limitations in mobility, pain, fatigue and fear of exacerbating muscle weakness. A survey of Irish Polio Survivors regarding exercise habits showed that 40% did not exercise at all, with only 30% managing to walk for at least 10 min, 3 days per week.

Exercise in Polio Survivors has been investigated in a small number of research studies. Further research is required and is currently ongoing (1, 2). Types of exercise include aerobic, strengthening and flexibility exercise. Polio survivors have been shown to experience improved fatigue and quality of life following an aerobic exercise programme (3). Strengthening exercise can result in improved strength, but exercise should be carefully monitored and prescribed to avoid any potential exacerbation of muscle weakness. Swimming may be a particularly suitable form of exercise as the buoyancy of the water minimises stress on muscles and joints and has been shown to result in less pain. More research is required.

Polio Survivors who wish to undertake a new exercise programme, should consult with their doctor, to ensure that an increase in activity is safe for them. Ideally new exercise should be introduced under the guidance of a qualified health professional and should be individualised to abilities and needs.

References:

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Summary 31**THE PSYCHOLOGICAL ASPECTS OF POLIO SURVIVORS THROUGH THEIR LIFE EXPERIENCE****Alain Yelnik, MD, PhD¹; N. Bradai, MD¹; P. Sportouch, MD¹; I. Laffont, MD, PhD²**¹Service de MPR, GH Lariboisière – F. Widal, AP-HP, Université Paris Diderot, Paris, ²Service de MPR, Hôpital Gui de Chauliac, Université Montpellier 1, Montpellier France. E-mail: alain.yelnik@lrb.aphp.fr

After several decades of stability, polio survivors often experience new signs and symptoms of their condition, characterized by global and muscular fatigue, decreased muscular strength and pain. For some of them, the hypothesis of a real Post-Polio Syndrome is raised but the role of an underlying psychological component has been suggested.

The literature does not report a higher prevalence of psychological disorders (mood disorders, depression) in polio survivors than in the general population. Conversely, the psychological impact of the patients' decreasing abilities, regardless of the cause, is regularly reported. Most patients report a restricted involvement in their daily life activities.

It is essential to be aware of the patients' experience in coping with polio as children as well as the medical treatments they went through in order to better understand their various types of complaints. For many children, the long years spent in a hospital setting, leave a strong imprint in their mind. Children growing up with physical disabilities, often built-up strong personalities and are used to give their very best to be just like others. When the growth period comes to an end, it is time to give up and store away the cumbersome and ugly chest braces, orthotics and orthopedic shoes, always reminding patients and others around them of their physical differences, sometimes by taking some assumed risks and doing physical acrobatics. It is a key period, cutting the umbilical cord a second time around, the one linking the patient to the medical and family environment. Many polio survivors have had active and fulfilling lives without ever requiring any medical help until the embarrassing disorders came up: falls, loss of muscular strength, trauma destabilizing a fragile equilibrium... This life and medical record may explain some reluctance to go back to a medical environment.

Professionals should be aware of these possible specific and often bitter experiences. In order to provide the best therapeutic advice, it is essential to take the time and listen to patients in order to differentiate the underlying physical and psychological components in symptoms of pain and fatigue.

Summary 32**PARTICIPATION IN SOCIETY****Jan Lexell, MD, PhD, Professor of Rehabilitation Medicine, Medical director^{1,2}**¹Department of Health Sciences, Lund University and ²Department of Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden. E-mail: jan.lexell@skane.se

Participation in society, defined as an individual's subjective experiences of involvement in life situations, is often regarded as an ultimate goal of rehabilitation following an injury or a life-long disease. A high level of participation would mean that a person have the possibility to reach his or her aspirations and achievements. This, in turn, often means that their life satisfaction, defined as one's subjective contentment with life, is high. These two concepts are closely linked and often related to personal and environmental factors. To design rehabilitation interventions for people with post-polio, we need detailed knowledge of their participation and restrictions herein, as well as factors restricting their participation. The identification of factors that are related to restrictions in participation can also enable clinicians to distinguish "persons at risk". In a series of studies, we have investigated how people with post-polio, up to 2.5 years after an individualised, interdisciplinary rehabilitation program perceive their participation and problems with participation in life situations. A majority of the 160 participants in the survey perceived their participation as sufficient in most activities with no severe problems with participation. Most restrictions in participation were reported in the domains of Family role, Autonomy outdoors, and Work and education. The perception of severe problems with participation was most strongly related to insufficient instrumental support. This indicates that the amount of support that someone receives from another person to be able to do that one wants to do is an important factor for perceived participation. In addition, perceived participation and problems with participation in life situations were closely related to life satisfaction and to the perception of encountered environmental barriers. These results indicate that participation in society among people with post-polio is influenced by their perception of the environmental barriers they encounter and that participation in society is also a determinant of life satisfaction. This emphasizes that post-polio rehabilitation programs need to focus on areas of participation that are perceived as a problem and promote access to a supportive environment to enhance participation in society and thereby a high degree of life satisfaction.

FREE PAPERS
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)

THURSDAY SEPTEMBER 1, 2011 AT 9.00–10.00

Summary 33

QUALITY OF LIFE (QOL) FOR POST-POLIO SYNDROME: A NEEDS-BASED RASCH-STANDARD QOL SCALE

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Introduction: The prevalence of polio survivors has been estimated at 24 per 100,000, of whom three quarters are reported to experience Post-Polio Syndrome (PPS). This is characterized by fatigue and new muscle weakness. While these impairments and activity limitations are well catalogued, much less is known about the impact of the syndrome upon Quality of Life (QoL). Unlike Health related Quality of life, Hunt and McKenna's Needs-based QoL emphasizes the impact of the condition on the ability of the patient to meet their needs. The theoretical basis for the needs-based QoL instrument is that life gains its quality from the ability and capacity of the individual to satisfy his or her needs.

Methods: Qualitative interviews were undertaken with 45 patients diagnosed with PPS (confirmed history of polio, new muscle weakness and extensive fatigue after at least 15 years stability). The interviews were transcribed, and 72 statements potentially consistent with the needs-based approach were extracted to construct a draft questionnaire. This was made into a questionnaire pack along with comparative questionnaires which included the WhoQoL Bref, and the HADS. After cognitive debriefing, the questionnaire was posted to 319 patients, 271 (85%) were returned.

Results: The mean age of the 271 respondents was 66.7 years (SD 8.2), and almost two-thirds (64.9%) were female. The majority (80%) were retired. Data from the 72 items were first subjected to an Exploratory Factor Analysis, which identified a two-factor solution (RMSEA 0.32). The second factor was related mostly to fatigue, leaving a draft 41 item scale for QoL. Seven items were removed due to misfit to the Rasch model, four for local dependency and five for multidimensionality. The final 25 item scale (PP-QoL) showed good fit (Chi Square $p=0.01$), strict unidimensionality (t -test 7.01: CI 4.4–9.6), and a Cronbach's alpha of 0.87. With the latent estimate transformed to a 0–100 scale, the mean score was 56.9 (SD 18.5) and only 3.7% of respondents were at either the floor or ceiling of the scale. Correlations with the WHOQoL Bref Physical and Psychological domains were -0.478 and -0.524 , respectively. There was a significant association between the PP-QoL and HADS caseness for both anxiety and depression (ANOVA; $p<0.001$).

Conclusion: A 25 item needs-based QoL scale for post-polio has demonstrated excellent reliability, appropriate concurrent validity, and satisfies the rigorous standards of the Rasch measurement model. Given this, a raw-score to interval scale transformation is available (on a 0–100 scale) for parametric applications, and the calculation of change scores.

Summary 34

AN EXPLORATION OF DIFFERENT COPING STRATEGIES EMPLOYED IN THE MANAGEMENT OF POST-POLIO SYNDROME

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Introduction: Post-polio syndrome (PPS) is a long-term disorder which cannot currently be prevented or reversed. PPS is characterized by fatigue and research has suggested quality of life (QoL) can adversely be affected by PPS (e.g. On et al., 2006). Individuals may therefore need to develop coping techniques to adapt to life with PPS.

Aims: To examine QoL and explore coping styles employed by people with PPS, using qualitative interviews.

Methods: Participants were recruited at a supraregional polio clinic or via the British Polio Fellowship. Interviews were recorded with people who met Halstead and Rossi's (1985) diagnostic criteria for PPS. Qualitative analyses of these interview transcripts identified common coping styles amongst the sample and the factors that contribute to the development of these coping styles.

Results: Forty-five interviews showed a diversity of coping strategies, with no new strategies identified in later transcripts. Fatigue had a significant effect on QoL. Although there were individual differences amongst participants, most could generally be described as adopting an active-focused or sedentary-focused coping style. Active-focused participants tended to adopt physical exercise regimes and overexert during everyday activity. In contrast, those who were sedentary-focused were more likely to rest and pace effectively, use advanced planning such as prophylactic rest, use assistive devices, avoid activity and seek help from others. Positive coping strategies included improvisation, i.e. adapting tasks to make them more manageable; employing relaxation techniques; and social support, by sharing experiences with other PPS sufferers. Interviewees often referred to the benefit of an accepting mindset, and stoicism was reported to help some participants stay positive.

Conclusions: It is clear that PPS has a significant effect on QoL and that coping behaviours occurred in response to this. Two different models for coping with PPS emerged, which had both positive and negative impacts on activity, self confidence, independence and fatigue.

Summary 35**NEVER SECOND BEST? A NARRATIVE PERSPECTIVE OF THE SHAPING AND RECONSTRUCTION OF IDENTITY IN TWENTY POLIO SURVIVORS****Anne-Kristine Schanke, Head Psychologist, PhD, Associate Professor***Sunnaas Rehab. Hospital/Department of Psychology, University of Oslo, Norway
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Introduction: The study is based upon narrative, life-history interviews with 20 polio survivors.

Aims: The aim of the study is to get a deeper understanding of contracting and living with the late effects of polio. Based on experience as a psychologist using life-story interviews in the clinical setting, the study was conducted in order to get knowledge of how identity and self-images among polio survivors are shaped and reconstructed throughout life where the late effects of polio serve as a turning point for self-understanding.

Methods and material: The National Society for Polio Survivors in Norway conducted in collaboration with professionals a survey where 1,444 polio survivors participated. The following statement were included in the questionnaire: "I think I have been psychologically harmed by the treatment received at the time I contracted polio." Schanke et al. (1999) made a statistical analysis of the respondents' into two groups, those reporting being psychologically harmed by the early treatment (27%) and those who did not (73%). The study is based upon qualitative in-depth interviews with 20 polio survivors strategically selected who wanted to share the psychological impact of contracting polio. The methods used in analysing data are in accordance with the guidelines for the qualitative research interview.

Results: The study focuses on the forming and reconstruction of identity with the late effects of polio as an important turning point for self-understanding. In childhood and youth, the identities are described as adjustment-oriented. The subjects inhabit a dual world; the internal one, feeling different, and the external world, behaving as non-disabled. As adults, before the onset of the late effects of polio, they were all in the "normal mainstream" by confirming important aspects of their normal identity on par with other non-disabled people by means of marriage, parenthood and occupation. Their admittance to hospitals due to late effects of polio restored polio as an illness, but also enabled the emergence of the personal and emotional voices of the subjects through exchange of mutual consciousness with other polio survivors. This appears to contribute to personal growth.

Conclusions: The clinical implication from the study is that it is important to focus on the emotional and cognitive impact of early experiences in a narrative perspective for polio survivors in order to contribute to reconciliation with their life history.

Summary 36**FACTORS INFLUENCE THE QUALITY OF LIFE OF POLIOMYELITIS SURVIVORS AND THOSE EXPERIENCING POST-POLIO SYNDROME****Anita Atwal, Occupational Therapist***Brunel University, Kingston Lane, Uxbridge, Middlesex, England. E-mail: Anita.atwal@brunel.ac.uk*

Introduction: The purpose of this research is to explore quality of life for persons with polio and post-polio syndrome (PPS) in the United Kingdom. Whilst research has occurred in other countries exploring quality of life issues for persons with polio and PPS this has not been mirrored in the United Kingdom.

Aims: The research questions which were explored were; (1) How has your health affected the quality of life? (2) If you could change just one thing to improve your quality of life, what would it be?

Methods and material: This study uses conceptual analysis for both questions using terminology from the International Classification of Function. The respondents wrote unstructured responses to both questions. In total 327 respondents completed question one and 266 respondent's question 2. The average age was 54 years and 75% classified themselves as white British. Most of the subject reported to have had PPS ($n=244$).

Results: The findings from our study found that physical health impacted upon quality of life in a negative way. In particular the symptoms associated with PPS such as pain and fatigue impacted upon participation social and leisure activities as well as on daily occupations such as walking. Thus the factor that were viewed as enhancing quality of life were improving physical health, pain and fatigue management, mobility, better financial situation, environmental modification and attitudes of health care professionals.

Conclusions: Our research has highlighted that rehabilitation professionals need to specially focus on maintaining person's mobility, fatigue and pain to maintain and or improve quality of life. Persons with polio and PPS want to participate in chosen leisure and social occupations and this it is sentential that rehabilitation programmes ensure this goal is achieved.

**OUTCOME MEASURES
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)**

THURSDAY SEPTEMBER 1, 2011 AT 10.30–12.00

Summary 37**THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH****Frans Nollet, MD, PhD***Academic Medical Centre, Department of Rehabilitation, Amsterdam, The Netherlands**E-mail: f.nollet@amc.uva.nl*

The International Classification of Functioning, Disability and Health (ICF) (1) by the World Health Organization's (WHO) is a framework to characterize diminished functioning or disability. Whereas the International Classification of Disease (ICD) classifies diseases as causes of death, the ICF classifies health by accounting for functioning. The overall aim of the ICF classification is to provide a unified and standard language and framework for the description of health and health-related states.

The ICF consists of three key components: Body functions and structures, Activities, and Participation. Abnormalities in body functions and structures are referred to as impairments, defined as a significant deviation or loss of functions (e.g. muscle weakness) and/or anatomical structures (e.g. malformation). Difficulties in performing Activities, which reflect a person's individual functioning, are referred to as activity limitations (e.g. limitations in walking). Finally, Participation restrictions refer to the problems a person may experience in societal functioning, i.e. in involvements in daily-life situations (e.g. restrictions in community ambulation). These three components are summarized under the umbrella terms Functioning and Disability. They are related to and may interact with the health condition and with personal and environmental factors.

The concept of functioning within the ICF framework is different from the concept of quality of life. Whereas quality of life refers to global or highly personalized evaluations of functioning referring to satisfaction or feelings, the ICF assesses functional capacity, such as physical endurance and muscle strength, and the impact of health on the performance of activities and disability.

The ICF distinguishes two qualifiers for the activities and participation components. The 'capacity' qualifier describes an individual's ability to execute a task or action in a standardized environment. The 'performance' qualifier describes what an individual actually does in his or her current environment. For instance, a timed walking test is a capacity measure, whereas measuring moving around in daily life with activity monitoring is a measure of performance.

Key points:

- Given the different impairments, such as muscle weakness, endurance, fatigue, and pain, and the widespread functional restrictions that may persist in polio survivors and progress due to post-polio syndrome, the ICF framework enables a comprehensive description of disability in polio survivors.
- To allow comparison between studies in polio survivors, a standard set of outcome measures covering the most

relevant ICF concepts should be agreed upon and should be used in every study.

Reference:

1. International Classification Functioning, Disability and Health (ICF). World Health Organization, Geneva, 2001 <http://www.who.int/classifications/icf/en/>.

Summary 38**MUSCLE STRENGTH MEASUREMENTS IN POLIO SURVIVORS****Anita Beelen, PhD***Department of Rehabilitation, AMC Amsterdam, The Netherlands. E-mail: j.a.beelen@amc.uva.nl*

Many polio survivors are experiencing new or increased muscle weakness as a late-onset symptom of poliomyelitis. As the rate of progression is generally slow, ranging from 1.5% to 3% per year, highly sensitive measurements are required to demonstrate progression.

Various methods of strength assessment have been used in polio survivors, eg, manual muscle testing, hand-held dynamometry and fixed dynamometry with isokinetic, isotonic and isometric strength measurements. Manual muscle testing, with the scoring system of the Medical Research Council (MRC) has been known to be limited in its measurement range, especially in lower extremity muscle groups, has poor inter-rater reliability and limited ability to detect change. In polio survivors MRC-grading has often been used to assess the severity of polio residuals. Another frequently used method in clinical practice is hand-held dynamometry (HHD). This quantitative method has a limited measurement range with a ceiling effect at about 200–250 N, which makes it less suitable for lower extremity muscle groups. Furthermore reproducibility in polio survivors is poor and small changes in muscle strength of lower extremity muscles can not be detected with HHD. For HHD-measurements performed by the same examiner smallest real differences (SRD) for a single individual) ranges from 23 to 80%.

Fixed dynamometers have shown good test-retest reliability in polio survivors, however, the ability to detect small changes in strength within an individual is limited. For isometric knee extension strength SRDs range from 18 to 25%. For isokinetic knee muscle strength SRDs are somewhat larger (28 to 39%). Although fixed dynamometry has limited value to monitor muscle strength changes in individual polio survivors, the reproducibility is sufficient to evaluate changes in groups of subjects, with feasible sample sizes, in both follow-up and intervention studies.

Key points:

- Qualitative grading of muscle strength with manual muscle testing according to MRC can be used to assess severity of polio residuals.
- Measurements of muscle strength of lower extremity muscles in polio survivors should be performed with fixed dynamometry to obtain reliable strength values that can

be used to evaluate changes in groups of polio survivors and not in individual patients.

- Studies on reproducibility of strength measurements in polio survivors should include indices for reliability, measurement variability and minimally important differences in muscle strength.

Summary 39

OUTCOME MEASURES FOR FATIGUE USED IN POST-POLIO RESEARCH. A SHORT OVERVIEW

Gunilla Östlund, Licensed psychologist, PhD

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Fatigue is one of the most common symptoms in post-polio (PPS). In PPS research different fatigue instrument are used which can exacerbates comparison of results.

The database PubMed were searched using the words: post-polio, poliomyelitis, fatigue, questionnaires, scales and validity. Ten fatigue questionnaires used in PPS research and/or populations were found. Seven were validated in a PPS population: 1) Fatigue Severity Scale (FSS), 2) Fatigue Impact Scale (FIS), 3) Piper Fatigue Scale (PFS), 4) (Dutch) Short Fatigue Questionnaire (SFQ), 5) Nottingham Health Profile (NHP), 6) Polio Problem List (PPL) and 7) Visual Analogue Scale (VAS). Three were not validated: 8) Multidimensional Fatigue Inventory (MFI20), 9) Fatigue Questionnaire (FQ) and 10) Short Form-36 (SF36). Five were uni-dimensional: FSS, SFQ, NHP, PPL, and VAS. Four were multidimensional: PFS, FIS, MFI20 and FQ. SF36 is a quality of life questionnaire, however the variable Vitality has been used as a measurement of fatigue in PPS research. Fatigue were defined as: increase of Fatigue, General fatigue, Physical fatigue, Reduced activity, Reduced motivation, Mental fatigue, lack of energy and decrease of vitality. Impact was measured by FSS, FIS, MFI20 and severity by VAS and MFI20 and FQ. Reliability was assessed by Cronbach alfa. Validity were defined as concurrent, construct, discriminative, item discriminative or convergent. Good at detecting low thresholds were FSS, NHP, and PPL. Cut offs had FSS, FQ (¾) and VAS (4.4/10). The fatigue could occur the same day, the last month or the last three month. In order to select an appropriate instrument, it is paramount to first answer questions such as: What do we want to know: Fatigue level, change over time, impact or severity? Do we want to use it on individual or group level? When did the fatigue experience occur: Present, Last week or last month? The type of fatigue questionnaire dictates the answers.

Summary 40

OUTCOME MEASURES FOR PAIN

Troels Staehelin Jensen

Denmark

No abstract available.

Summary 41

OUTCOME MEASURES FOR PHYSICAL FUNCTIONING IN POST-POLIO RESEARCH

Merel Brehm, PhD; Anita Beelen, PhD; Frans Nollet, MD, PhD

Department of Rehabilitation, Academic Medical Center, The Netherlands. E-mail: m.a.brehm@amc.uva.nl

Physical functioning is an important health outcome in post-polio research, and many instruments have been developed to measure it. However, clear recommendations regarding which outcome measures to use are lacking. This makes it difficult for researchers and clinicians to decide which one is most suitable for a certain purpose.

According to the ICF, physical functioning mainly bears on the domain of mobility, including the items 'walking' and 'moving around'. Important aspects that relate to 'walking' contain endurance, distance, and speed. These aspects can be assessed with time-scored walking capacity tests, measuring what a person is capable of doing in a standard environment. Based on the literature, the 2-minute Walk Test (2MWT) at maximal speed is recommended as most reliable for this purpose. This test is objective, free of reporting bias, easily reproducible, and clinically relevant. However, it remains questionable whether its responsiveness is sufficient enough to pick up the small changes that are often seen in persons with post-polio syndrome (PPS). Alternative tests may be the 6MWT at self-preferred speed, or the shuttle walk test (SWT) at fixed or increasing speed. Yet, for more severely affected PPS patients these tests may be too demanding. Moreover, the feasibility and validity of SWTs in PPS patients is unknown.

Since characteristics of walking under standardized conditions may differ from those in daily-life, an assessment of actual walking in the patients' own environment, i.e. walking performance, is also needed. This is especially important given the moderate relationships that have been demonstrated between capacity (can do) and performance (do do). Activity monitoring can be used to objectively measure walking performance. Walking performance can also be perceived with questionnaires, such as with the physical functioning subscales of the Sickness Impact Profile, and the 36-Item Short-Form Health Survey (SF36-PF). We recommend using the SF36-PF scale. This recommendation is based on previous research, showing that changes in walking capacity are (non-significantly, although a trend is found) related to changes in physical functioning. Nonetheless, it must be noted that the responsiveness of the SF36-PF scale is limited.

Key points:

- The 2MWT at maximal speed is recommended as preferred outcome measure to evaluate walking capacity in post-polio research.
- The 6MWT at self-preferred speed, or the incremental SWT, for which the validity should be investigated in future research, may be interesting alternatives.
- Walking performance, as perceived by the patient, should be preferably assessed with the SF36-PF scale.

Summary 42

OUTCOME MEASURES FOR PARTICIPATION AND QUALITY OF LIFE IN POST-POLIO RESEARCH

**Katharina Stibrant Sunnerhagen, MD, PhD,
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The first issue is if participation and quality of life is different for persons with polio than for other persons. If we believe so, there is a need for specific instruments to be used in research regarding life of polio survivors. If we believe that having had polio is one aspect of life on the person with polio, than we can apply the same instruments as for other people and discuss and compare.

In most of the research performed the latter situation is the common one; i.e. using the same instruments as elsewhere. However, if this is because there have been not many disease specific instruments around or if the researcher has made a specific choice based on ideas is not known. Often when there are disease specific instruments available, the project contains both generic instruments to allow comparisons between groups and disease specific ones. The latter are said to be more specific to changes due to the disease (such as an intervention).

Not many questionnaires address participation so often there are surrogate measures presented such as work capacity, need for assistance in daily activities. The Impact on Participation and Autonomy, which is the first questionnaire based on the ICF terminology, has been used in polio.

For health-related quality of life in polio research, many groups have used the Nottingham Health Profile or the Short Form 36. The first has better psychometric qualities and is based on the opinions of persons living in the community as well as information from general practitioners what problems his patients are complaining about. Later on in this session, a new instrument that aims to assess quality of life in polio survivors will be presented.

The important thing is to use an instrument which is appropriate to the population and is correctly translated. The questions of cultural and ecological validity need to be addressed. There is a benefit if there are norm values.

There is not known if the participation and quality of life is different for those who have had polio compared to healthy persons or compared to other persons living with chronic diseases.

There is a need for further research regarding this. The opinions of those living with polio needs to be addressed. The involvement of persons living with polio in research is needed.

**SYMPTOMS AND MANAGEMENT 1
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)**

THURSDAY SEPTEMBER 1, 2011 AT 13.00–14.30

See summary 21

**ORTHOPEDIC SURGERY IN POST-POLIO
SURVIVORS**

Anders Stenström, MD, PhD

*Department of Rehabilitation Medicine, Skåne University
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See summary 22

**ANESTHESIA ISSUES FOR POST-POLIO
SURVIVORS**

***Selma Harrison Calmes, MD, Clinical Professor
of Anesthesiology (Retired)***

*University of California at Los Angeles School of
Medicine, Los Angeles, CA, USA*

See summary 23

RESPIRATION AND SLEEP

Michael Laub, MD, PhD, Dr med Sc

*Respiratory Centre East, Rigshospitalet, Copenhagen
University Hospital, Copenhagen, Denmark*

Summary 24

SPEECH AND SWALLOWING

Svend Prytz, MD

Denmark

No abstract available.

**SYMPTOMS AND MANAGEMENT 2
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)**

THURSDAY SEPTEMBER 1, 2011 AT 15.00–16.30

See summary 28

VOIDING AND BOWEL PROBLEMS

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See summary 25

FATIGUE – SYMPTOMS AND MANAGEMENT

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See summary 26

PAIN IN POLIO SURVIVORS

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Professor in Rehabilitation Medicine**
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Summary 43

**MANAGING THE COMPLEXITY IN DAILY
OCCUPATIONS**

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Occupations are the ordinary and familiar things that people do every day in interaction with the environment. Late effects of polio, also referred to as post-polio syndrome, may affect the ability to perform occupations in everyday life. The new symptoms such as increased muscle weakness, fatigue, and muscle or joint pain challenge persons to change their behavior, and to reexamine earlier expectations, ideals, and goals.

This presentation is based on a review of the literature, own research and clinical experiences from a polio clinic. The purpose is to describe strategies that persons with late effects of polio use in everyday life to manage their daily occupations.

A variety of strategies is used but a salient strategy among persons with polio is their maximization of their physical capabilities, their willingness to exert themselves in performing occupations. Their willpower to fulfill goals, carry out occupations and live a “normal life” seems to lead to their ignoring their symptoms. New types of strategies such as conserving energy, moderating occupations and using assistive devices imply accepting a changed lifestyle. Such acceptance may be a long, drawn-out process. People need time to realize both the shift in their capabilities and their own patterns of occupations in everyday life before they can change their approach. In this process social support from family and friends as well as institutional support from health professionals and information are important.

Time, energy, ability to solve problems, accessible environments, access to information and support, and readiness to compensate with assistive devices are essential factors for adaptive behavior in daily occupations.

Occupations are complex because they have diverse meanings with social as well as individual significance. In clinical practice, therefore it is essential to obtain an understanding of each person’s reasoning in their daily occupations. Identifying and emphasizing all signs of problem-solving efforts and energy-saving strategies that people use should confirm a person’s faith in her or his own ability to make changes in daily life. This would gradually pave the way for flexibility in strategy use thereby facilitating participation in daily occupations.

FREE PAPERS
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)

THURSDAY SEPTEMBER 1, 2011 AT 9.00–10.00

Summary 44

EFFECTS OF RESISTANCE TRAINING IN COMBINATION WITH IVIG TREATMENT IN PATIENTS WITH POST-POLIO

Katarina Skough, Physiotherapist, PhD student
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Introduction: Studies have shown that muscle resistance training in patients with post-polio syndrome (PPS) increases strength and/or performance. Also intravenous immunoglobulin treatment (IVIG) leads to beneficial effects. One may speculate that there are different mechanisms behind the clinical effects of the treatment with IVIG and the effects of muscular resistance training.

Aim: Evaluate the effects of muscular resistance training for PPS patients who receive treatment with IVIG on muscle strength, functional ability, health-related quality of life, pain and gait variables.

Methods and material: The study is a clinical open prospective study with a randomisation of IVIG-treated PPS patients to either muscular resistance training or to continue with "business as usual".

The patients included, with clinically and neurophysiologically verified diagnosis of PPS, were referred for IVIG treatment and were able to walk for 6 min.

Resistance training was performed with a physiotherapist three days a week during 12 weeks.

All patients were evaluated before the treatment and after the 12 weeks with: 6-minute walk test, timed up & go test (TUG), muscle strength of the knee extensors and flexors measured with dynamic dynamometer (KinCom) and questionnaires short-form SF-36, EQ5D, The Physical Activity Scale for the elderly (PASE). The Multidimensional Fatigue Inventory (MFI-20) and pain measured with visual analogue scale (VAS).

Results and discussion: Seventeen patients participated. 6-minute walk test showed an increase of walk length of 26 m for all. There was a better result for the training group than for the control group regarding muscle strength in knee extensors (involved leg). There was a statistically significant improvement for the training group regarding General Health (SF36) and for General Fatigue (MFI-20) compared to the control group.

Summary 45

INTRAVENOUS IMMUNOGLOBULIN FOR POST-POLIO SYNDROME: A DOUBLE-BLIND, PLACEBO-CONTROLLED, RANDOMIZED TRIAL

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²*Hospital of Malcesine, Italy*

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Introduction: Post-polio syndrome (PPS) is a neuromuscular disease affecting polio-survivors. The cause of PSS remains unclear. Three prevailing hypotheses have been advanced: stress-induced degeneration of surviving neurons, persistent poliovirus replication or reactivation and immune-mediated damage. Immunological activation in PPS has been demonstrated in previous studies, so intravenous immunoglobulin (IvIg) are being tempted as therapeutic options, with some positive results.

Aims: To evaluate safety and efficacy of IvIg as treatment of PPS.

Methods and material: We performed a double-blind, randomized, placebo-controlled pilot study with 50 patients to investigate possible clinical effects of IvIg in PPS. Twenty-five patients were randomized to either IvIg (0.4 mg/kg/day for five days) or placebo (saline). Fifty PPS patients were included in the study. At baseline all patients sustained a full physical, neurological, neurophysiological examination and study assessment: quality of life measured with Short-Form 36 questionnaire, fatigue with Fatigue Severity Scale, pain with Visual Analogue Scale and 101-Point Numerical Rating, Muscle strength with MRC scale and with dynamometer, physical performance with 6-Minute Walking Test. Infusion of IvIg or placebo was started in Malcesine Hospital during 5 consecutive days. After 2 and 4 months, neurological examination, study assessment and neurophysiological study were repeated.

Results: Our data suggest that patients receiving IvIg reported a significant intragroup improvement in quality of life ($p < 0.05$). IvIg was well tolerated.

Conclusions: IvIg may have a clinically relevant effect in patients with PPS, with improvement in quality of life. The effect may be due to a decrease in inflammatory process at spinal level.

Summary 46**OUTCOME OF PHYSIOTHERAPY AS PART OF A MULTIDISCIPLINARY REHABILITATION IN AN UNSELECTED POLIO POPULATION WITH ONE YEAR FOLLOW-UP – AN UNCONTROLLED STUDY****Susse Broberg, PT**

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Introduction: The study was carried out as a prospective uncontrolled intervention study at the PTU Rehabilitation Centre – an outpatient centre in Copenhagen. The physiotherapy offered to patients with polio is based on knowledge of best practise but the results of the intervention have not yet been documented.

Aims: The aim of this study was to evaluate outcome of physiotherapy as part of a multidisciplinary rehabilitation.

Methods and material: Fifty patients with late effects of polio, first time referred to physiotherapy at the PTU Rehabilitation Centre was included. The intervention was physiotherapy as an essential part of an individually planned multidisciplinary rehabilitation. The outcome measures Six Minute Walk Test and Timed-stands Test were used to assess the functional capacity. Quality of Life was evaluated by Medical Outcome Survey Short Form (SF-36) and Fatigue by Multidimensional Fatigue Inventory (MFI-20). Patients were tested at baseline; three months after start of rehabilitation and at one-year follow-up.

Results: The polio patients showed significantly better functional capacity on all measurements three months after start of intervention and at one-year follow-up. In quality of life the patients showed significant improvement in the SF-36 dimensions “Bodily Pain”, “General Health” and “Vitality”, but only the improvement in “General Health” remained after one year. Fatigue, measured on MFI-20 showed significant improvement on “Physical Fatigue” after intervention, but not at one-year follow-up.

Conclusions: This study shows that patients with late effects of polio, who experience new problems related to polio, can benefit from an individually planned multidisciplinary intervention with emphasis on physiotherapy, and the improvement can remain at one-year follow-up.

Summary 47**HOME VENTILATOR USER SURVEY: A PEEK INSIDE VENT USERS’ THOUGHTS****Barbara Rogers, Patient Advocate, Patient Perspective Consultant, Vent user**

New York, USA. E-mail: brogers@necaweb.org

Introduction: There had not been a U.S. needs assessment survey of home ventilator users for a long time. This survey was created initially for a lecture at CHEST 2010 where preliminary data was presented.

Aims: This survey was developed to gather data in the U.S. and selected countries to better understand needs and challenges of ventilator users and to gain insight into how vent users services and lifestyles may differ between the samples.

Methods and material: The International and U.S. samples were distributed on the Internet through recognized ventilator users’ support groups/clinician resources. In the U.S., a paper questionnaire was also distributed by mail through durable medical equipment providers utilizing insurance billing codes to identify appropriate clients.

Key findings: Significant and relevant key findings from 281 respondents (231 US/50 International) to the 55 question survey include the following differences between the International and U.S. samples:

- Use of NIV - International users – 70% vs. 53% U.S. users
- Type of tracheostomy tube used – cuffed: 50% International vs. 17% U.S.; uncuffed: 67% International vs. 33% U.S.
- Type of noninvasive interface used – while majority of both samples used masks/pillows/or prongs (78% both), mouthpiece was significantly more used Internationally – 25% International vs. 7% U.S.
- Vent users who were unaware of ventilator mode used – 43% International vs. 27% U.S.

Relevant differences:

- Both samples reported receiving approximately 25% less nursing care than they are eligible for – International received 74% of eligible and U.S. received 77% of eligible.

Conclusion: There are significant and relevant differences in components of care between International and U.S. responders which bear further research to determine their causes. Improved long-term outcomes through better patient and provider education may follow.

AGING
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)

THURSDAY SEPTEMBER 1, 2011 AT 10.30–12.00

Summary 48

GENERAL PERSPECTIVES OF AGING

Kirsten Avlund, OT, Professor, Dr Med Sci

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The way we age have very different pace and courses, because the aging process is influenced by many individual and external factors: e.g. genetics, socioeconomic status and disease experiences throughout life, psychological factors, medical care, rehabilitation and preventive services. The aging process proceeds differently in men and women and varies from one birth cohort to the other.

Three terms are commonly used to identify vulnerable older adults: frailty, comorbidity and disability. Frailty is a physiological state of increased vulnerability to stressors that results from decreased physiologic reserves, and even dysregulation, of multiple physiologic systems. Comorbidity is defined as having two or more diseases and disability as difficulty or dependency in carrying out activities essential to independent living, including essential roles, tasks needed for living independently in a home, and desired activities important to one's quality of life.

It may be important also to study early signs of frailty and disability, as these factors are multifactorial, including physiological, psychological and social risk factors. It is possible that there are some early signs that can be measured but which are not yet manifested. Such early signs may be useful to identify individuals at high risk of functional decline before it actually occurs by characterizing early functional states that are associated with later disability. For many individuals with co-morbidity and complex problems, targeting a single risk factor may have little value. Consequently, it may be important to explore common factors that increase the risk of disability, regardless of specific causes. Recent research has shown that unexplained fatigue may be such a factor.

Further, the importance of physical activity for slowing down the speed of the aging process has been shown again and again, but it is also important to be aware of the fact that also a strong social network is important for keeping up a good functional ability.

Key points:

- Be aware of unexplained fatigue and react, if you feel more fatigued than you used to.
- Be aware of the importance of physical activity no matter whether you have a disease or not.
- Be aware of the importance of keeping up a strong social network.

See summary 32

PARTICIPATION IN SOCIETY

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See summary 27

IMPACT OF COMORBIDITY, AGING AND LIFESTYLE-RELATED FACTORS IN POLIO SURVIVORS

Irene Tersteeg, MD; Janneke Stolwijk, MD, PhD; Anita Beelen, PhD; Frans Nollet, MD, PhD

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Summary 31

THE PSYCHOLOGICAL ASPECTS OF POLIO SURVIVORS THROUGH THEIR LIFE EXPERIENCE

Alain Yelnik, MD, PhD¹; N. Bradai, MD¹; P. Sportouch, MD¹; I. Laffont, MD, PhD²

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**MOBILITY
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)**

THURSDAY SEPTEMBER 1, 2011 AT 13.00–14.00

See summary 29

FALLS AMONG POLIO SURVIVORS

Alice Bickerstaffe, MD; Anita Beelen, PhD; Frans Nollet, MD PhD

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Summary 49

LEG ORTHOSES FOR POLIO AND POST-POLIO SYNDROME: NUMEROUS INNOVATIONS, LIMITED EVIDENCE

Merel Brehm, PhD¹; Jaap Harlaar, PhD²; Kees Noppe, CPO³; Frans Nollet, MD, PhD¹

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The number of studies on the effectiveness of leg orthoses for patients with polio and other causes of non-spastic paresis is very limited. The need for such studies however increases, because new and costly technologies become available, such as stance control knee-ankle foot orthoses (SC-KAFOs), and prepreg carbon composite shell materials. Moreover, in many countries reimbursement will become increasingly dependent on proven (cost-)effectiveness of these new devices.

Preferably, an orthosis should be effective in achieving its aim, which usually is improving walking or standing. At the same time, it should hamper walking as little as possible, for instance by its weight or by the resulting changes in the gait pattern, which may lower walking speed and increase energy cost (EC) of walking.

Gait analysis can be used to determine the gait abnormalities underlying the complaint of the patient, which may range from falling and fear of falling to muscle overuse symptoms, and decide on the required action of the orthosis. In research,

quantitative gait analysis enables the determination of the biomechanical efficacy of an orthosis, which can be related to the clinical effectiveness (1).

Studies so far have shown that carbon composite KAFOs, designed based on gait analysis, are less energy demanding to walk with, compared to conventional leather-metal and less rigid polypropylene orthoses (2). This is clinically relevant in view of the post-polio syndrome (PPS), which is characterized by a slow decline in muscle strength, and, hence, a decline in physical capacity. Lowering the physical demands of walking by reducing EC may improve functioning in PPS. Studies have also demonstrated that ankle foot orthoses (AFOs) that restore the foot rocker, increase walking speed and reduce EC of walking. The same is true for SC-KAFOs, compared to conventional locked-KAFOs.

More research is needed to determine the effectiveness of (different types) of leg orthoses in polio and PPS. Because orthotic research is very laborious, and large numbers cannot easily be collected, multicenter studies should preferably be conducted. Furthermore, to facilitate comparison between studies, core sets of outcome measures, to be used in orthotic studies on AFOs and KAFOs should be agreed upon (3).

Key points:

- Despite innovative technological advancements, studies on the effectiveness of leg orthoses in polio are scarce.
- Improvement of orthoses reduces EC of walking, which may improve functioning.
- Multicenter studies and the use of core sets are advocated to increase the evidence for the effectiveness of orthoses.

References:

- 1 Harlaar J, Brehm M, Becher JG, Bregman DJ, Buurke J, Holtkamp F, De Groot V, Nollet F. Studies examining the efficacy of ankle foot orthoses should report activity level and mechanical evidence. *Prosthet Orthot Int.* 2010; 34: 327–335.
- 2 Brehm MA, Beelen A, Doorenbosch CA, Harlaar J, Nollet F. Effect of carbon-composite knee-ankle-foot orthoses on walking efficiency and gait in former polio patients. *J Rehabil Med* 2007; 39: 651–657.
- 3 Brehm M, Bus SA, Harlaar J, Nollet F. A Candidate Core Set of Outcome Measures based on the International Classification of Functioning, Disability and Health for Clinical Studies on Lower Limb Orthoses. *Prosthet Orthot Int* (in press).

Summary 50**A SYSTEMATIC SEATING ASSESSMENT*****Anna-Lene Hartvigsen, Physiotherapist****PTU Rehabilitation Centre, Denmark. E-mail: alh@ptu.dk*

Many of the polio survivors treated at the PTU have problems concerning seating in either their wheelchairs or in ordinary chairs. Several polio survivors have gained an asymmetric body posture due to their polio paralysis in the trunk, pelvic region and lower extremities.

On this basis, we have developed a systematic seating assessment over the course of the past years. Our aim is to provide the polio survivor and the therapists with the best knowledge of solution to the seating problems.

The Seating Assessment: Interview: The interview is very important. We attempt to gather information about the daily problems and systematically go through the daily living of the polio survivor. Furthermore, we ask about possible pain and fatigue, the family situation, housing, job, leisure time etc.

Mattress Assessment: After a very thorough interview we make an assessment of the standing position and a mattress assessment covering the entire body and the joints. We examine the range of movement in the major joints and balance and look for deformities and asymmetry. For this assessment we use various tools: 1. A firm surface for the polio survivor

to sit and lie on. 2. Camera – with permission from the polio survivor. 3. Small stickers to mark different landmarks in the skeleton. 4. Interface Pressure Mapping.

Plan: After the assessment we create a report with pictures and conclusions from the assessment. This report is thoroughly reviewed by the polio survivor and the therapist in order to make a plan together.

Solutions: After the Seating Assessment we attempt to solve the problems with different devices. There are a big variety of technical solutions such as small foam triangles placed under the oblique pelvis in an ordinary chair, several adjustable wheelchair cushions, seat castings and custom-built wheelchairs. It is important that the polio survivor try the chosen device for about a week at home/job.

Conclusion: The Systematic Seating Assessment is an important tool for the polio survivor and therapist to obtain a comprehensive background finding solutions to the seating problems. It is very important to emphasize all three dimensions equally to get the optimal results. It is also important in the interview to understand the complete life situation of the polio survivor in order to understand his/her circumstances. The thorough mattress assessment provides the therapist with further knowledge to solve the problem. Finally, it is important that the polio survivor fully understands the plan.

**EXERCISING
(PRIMARILY FOR HEALTH CARE PROFESSIONALS)**

THURSDAY SEPTEMBER 1ST 2011 15.00–16.30

Summary 51**THE ROLE OF EXERCISE IN INDIVIDUALS WITH LATE EFFECTS OF POLIO****Carin Willén, RPT, PhD**

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The role of exercise in the management of individuals with late effects of polio is controversial which reflects the concern that overloading muscles with new weakness might lead to further decreased function. However, studies have demonstrated positive effects of physical exercise as concerns muscle strength as well as general physical activity.

When a person with late effects of polio engages in muscle-building exercise, it seems as though the first effect is improved neural activity. If the muscle cells are already very large, it is unlikely that they will increase in size. As the strength of an extremity can vary because different groups of muscles can be more or less affected after polio, it is likely that the “weakest” muscles create a limitation and the “stronger” will not be enough exerted. Hence, the effect of exercise on the latter muscles will be like the one on inactivated non-polio muscles. The damaging effects of too much activity have been discussed. They are likely to occur as a result of excessive intensity and duration and can lead to tiredness and weakness that continues for several days. Whether this creates lasting damage is unclear, but unlikely.

Physical exercise and activity should firstly be seen as preventative (against lifestyle illnesses) and secondly retentive, in order to maintain functioning and activity and also to prevent the occurrence of new symptoms. When planning exercise, polio status and reduced strength must be taken in to consideration. Training must be individualized and the clinical and functional goal identified. The person’s reactions to training should govern its planning.

Key points:

- The first effect of strengthening exercises is increased neural activity.
- Overloading of muscles is reversible if detected in time and motivates adjusting of the exercise program and physical activity.

To adapt the level of physical activity do not mean that exercising should be avoided, not that the total amount of time spent on physical activity must be altered but the activities might be performed at a lower level and be paced.

Further research is needed to obtain knowledge about the long-lasting effects of physical training.

Summary 52**ROLE OF AEROBIC EXERCISES ON FUNCTIONAL CAPACITY, SYMPTOMS AND QUALITY OF LIFE IN PATIENTS WITH POST-POLIO SYNDROME****Jülide Öncü, MD, PMR Specialist**

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The term post-polio syndrome (PPS) was first launched in 1985 by Halstead to cover all aspects of late consequences occurring several years after acute paralytic polio (Halstead and Rossi 1985). The symptoms included were new weakness, generalized fatigue, decreased muscular endurance, muscle and joint pain and cold intolerance resulting decline in functional capabilities of these patients.

The negative effects of inability can be accentuated with the late sequelae of poliomyelitis. As a result most of these patients have poor level of cardiopulmonary functioning. Cardiopulmonary dysfunction associated with PPS and response to aerobic exercise training are rarely described in the literature other than neuromuscular problems. Maximal oxygen consumption during exercise was found to be significantly reduced in PPS patients when compared with healthy age-matched subjects. And this situation eventually has a negative impact on the quality of life of these patients. Therefore, cardiovascular training should also be incorporated into each patients exercise prescription.

In the literature studies related to aerobic conditioning including arm ergometry, leg ergometry and aquatic exercises showed improvement in endurance and functional capacity of these patients. Current evidence suggested that carefully prescribed and supervised aerobic exercise designed specifically to the patient with submaximal intensity (heart rate reserve should not exceed %70 or according to Borg Rated Perceived Exertion Scale should not above 13) provides improvement in muscle endurance and cardiopulmonary conditioning without the risk of overuse damage. As in our study of 32 PPS subjects were divided into two groups for either hospital or home-based aerobic exercise programmes with submaximal workload and specifically prescribed for the patient. We showed that fatigue and quality of life were both improved in two groups; functional capacity increased in hospital-based group; so we concluded that regular aerobic exercise decreases fatigue; improves functional capacity and quality of life in PPS at least in short-term period especially when undertaken in hospital under supervision. But it should be emphasized that for the long-term effects of aerobic exercises; further studies are needed.

Since for many patients with PPS the recurrence of weakness, pain and fatigue is very distressing, aerobic exercise has paramount importance with regard to remaining independent routine daily activities. As emphasized in the report of EFNS task force; it is very important that most exercises have been

executed with supervision, submaximal workload, intermittent breaks and rest periods between sessions to prevent the likelihood of overuse effects.

Fatigue and decrease in functional capacity are the most important features of PPS and cause restrictions in daily activities.

Summary 53

HOW TO TARGET AEROBIC EXERCISE TRAINING IN POLIO SURVIVORS

Eric L. Voorn, MSc^{1,2}; Merel A. Brehm, PhD¹; Frans Nollet, MD, PhD¹; Anita Beelen, PhD¹

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According to guidelines of the American College of Sports Medicine (ACSM), target intensity for exercise training aimed at increasing aerobic capacity is generally based on the maximal aerobic capacity. The ACSM recommends an intensity that is equal to or just below the anaerobic threshold (AT). The AT is defined as the upper limit of exercise intensity that can be sustained aerobically, and occurs, depending on a person's initial fitness level, between 40% and 85% of oxygen uptake reserve (VO_2R) or heart rate reserve (HRR). In persons with Postpoliomyelitis Syndrome (PPS), the ACSM recommends an exercise intensity of 40% to 70% of VO_2R or HRR, depending on the (recent) history of weakness and symptoms (ACSM, 2003; Birk & Nieshoff, 2004).

Maximal aerobic capacity is usually assessed through graded maximal exercise testing. However, in patients with

PPS maximal exercise testing may result in excessive fatigue and prolonged recovery. Therefore, professionals are rather reluctant to prescribe these tests in patients with PPS, which makes it difficult to establish VO_2R and HRR. Predicting maximal aerobic capacity, from heart rate during submaximal exercise using the Astrand-Rhyming nomogram may not be valid in patients with reduced muscle mass due to PPS. Alternatively, since the AT is reached below maximal work intensities, submaximal exercise testing may be used to assess AT in patients with PPS. A non-invasive method to estimate the anaerobic threshold involves the ventilatory threshold (VT) by measurement of ventilatory and gas exchange variables. Unpublished data from 30 patients with PPS have shown that using this method, the VT could be determined in the majority of patients (2/3) (unpublished data, 2010; Willén et al., 1999).

Accordingly, when determining the target intensity for aerobic exercise training in persons with PPS, it is recommended to use the VT assessed with submaximal exercise testing. For patients in which the VT cannot be determined, or when gas-analysis equipment is not available, intensity should be guided based on ratings of perceived exertion (e.g. between ratings of 11 to 14 at the 15-point Borg Scale) or estimated HRR (e.g. between 40% to 70% of HRR). However these methods have not been validated in PPS. Future research should focus on investigating these methods and alternative methods to determine aerobic exercise intensity in patients with PPS.

Key points:

- Exercise intensity for aerobic training in patients with PPS should be preferably based upon the ventilatory threshold (determined by submaximal exercise testing).
- Future research should focus on developing alternative methods for assessing aerobic exercise intensity in patients with PPS for whom the VT cannot be determined.

ORTHOTICS (WITH TRANSLATION)

FRIDAY SEPTEMBER 2, 2011 AT 9.00–10.00

Summary 54

ORTHOSIS MANAGEMENT IN PATIENTS AFTER POLIOMYELITIS ANTERIOR ACUTA

Barbara Bocker, MD; C. Hölig; U.C. Smolenski, MD
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Objective: The effect of orthosis supply in patients with paresis caused by poliomyelitis has to be proved. The questions are, if orthosis supply improves the bodily functionality especially the muscle activity of lower limb and trunk.

Subject: In 13 patients with partial paralysis of the quadriceps muscle and weakness of the dorsal flexors of the foot and instability of the knee joint caused by poliomyelitis anterior acuta there was indicated a femoral orthosis supply. Ten of them fulfilled the inclusion criterias for the study.

Method: The effect of a femoral orthosis on the paretic limb had to be described by the surface EMG-activity of specified leg and trunk muscles before and after orthosis supply. By means of the kinematic gait analysis the knee joint angle and the stance duration of every single leg was detected before (t0) and immediately after orthosis supply (t1) as well as after gait training (t2).

Results: Because of 4 dropouts 6 patients were observed with the orthosis in a time of 6 months until follow-up of the monitoring. On the side without orthosis, increased EMG values of both abdominal muscles and *m. gluteus medius* during standing and of the *mm. multifidii* during walking were observed. On the side with orthosis support no changes during standing were found, but during walking *m. abdominalis obliquus externus* showed higher EMG-level whereas *m. biceps femoris* had decreased values. The knee joint angles showed an increase in the leg with the orthosis of 20° without any hyperextension but only the tendency of rising in the duration of the stance phase was seen in the leg with orthosis.

Conclusion: The instable knee could be stabilized by adequate orthosis. Orthotic support of the paretic limb is able to relieve the overstrained *m. biceps femoris* but a sufficient activity of the *m. gluteus medius* at the stable leg and of the abdominal musculature on both sides is necessary to estimate to indicate orthosis supply.

Discussion: First orthosis use can cause difficulties for the patient because of the new muscle stereotype. More studies with higher patient numbers and further parameters of daily living are in progress to find out, which requirements of muscles strength of lower limb and trunk as well as which exercises are necessary to prepare an orthosis accommodation sufficiently.

Key points:

- Poliomyelitis
- Orthosis
- Requirements and management of use.

Summary 55

LIGHT WEIGHT FULL CONTACT CARBON LEG ORTHOSES FOR POLIO AND POST-POLIO SYNDROME

Kees Noppe, CPO¹; Frans Nollet, MD, PhD²

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Many polio survivors including those with post-polio syndrome use leg orthoses for walking and standing. The prescription of an orthosis requires a thorough analysis of functioning and a careful physical examination. It is important to analyze the complaints carefully and judge whether an orthosis will be really helpful and possible.

Gait analysis is often used to determine the precise gait pattern abnormalities. Based on this the orthotic requirements are decided. An orthosis should preferably only support or stabilize joints during the appropriate phase of the gait cycle. Specific consideration must be given to the anticipated changes in gait pattern and whether patients are capable to change their gait accordingly.

An important development over the past fifteen years in our manufacturing process is the application of light weight full contact orthotics made of prepreg carbon composites. These materials enable the construction of rigid, strong and light-weight orthoses. Advantages are that optimal correction and stability can be achieved through total contact fitting and less weight has to be carried by the paretic muscles. Another advantage is that the thin shelves often allow the use of normal shoes, except in cases of severe deformities and large leg length discrepancies. A limitation however is that this technique is very demanding to the orthotist. The carbon material cannot be corrected afterwards and the position of the hinges cannot be altered once placed. Application of this technique requires that joint movement resulting in position-dependent deformities have to be prevented especially around the ankle. Therefore, ankle hinges that limit dorsiflexion are usually applied. An advantage of these hinges is also that they can be used to restore foot rocker during stance in cases of weak plantar flexors.

The manufacturing of full contact carbon orthoses follows a fixed order. It begins by making a plaster model of the leg. From this model a polypropylene test socket is made. If the test socket fits well, the carbon orthosis is made in two stages.

The major types of orthoses are ankle-foot orthoses (AFOs) and knee-ankle foot orthoses (KAFOs). For KAFOs several stance control knee joints have become available over the past years, and new developments in this area are foreseen.

Key points:

- New manufacturing methods of leg orthoses using carbon composites are beneficial for polio patients.
- Manufacturing of carbon orthoses should be centered to ensure high quality of devices.
- Best results are achieved when orthotists, rehabilitation doctors and physical therapists work closely together.

FREE PAPERS

FRIDAY SEPTEMBER 2, 2011 AT 9.00–10.00

Summary 56**EVALUATION OF THE FUNCTION OF PELVIC FLOOR MUSCLES IN THE PATIENTS WITH POST-POLIO SYNDROME****Mirca Ocanhas, Mestre em Ciências, PT***Universidade Federal de Sao Paulo – Neuromuscular diseases sector, UNIFESP, Brazil**E-mail: mirca.ocanhas@uol.com.br*

Introduction: Vast pelvic floor (PF) muscle function and dysfunction literature shows a great prevalence in functional and anatomical alterations of the urinary, fecal, sexual/gynecological systems. However, rare pelvic muscle function and dysfunction studies in neurological patients are available.

Purpose: Evaluating the conditions of the PF musculature and identifying factors related to weakness in this musculature, severity and onset of symptoms, a physical therapeutic evaluation was developed, adapted for use in patients with a neurological entity. Quantitative evaluation of strength and resistance of PF muscles, and the correlation of Functional Evaluation of Pelvic Floor (FEPF) with manometry.

Methods: Eighty-three patients with PPS, more than 15 years after their acute polio episode. The patients were physical therapeutic evaluation form of functions of PF muscles, regarding the existence of complaints related to the urinary, fecal, sexual/gynecological systems. Specific clinical tests were carried out (visual inspection and palpation), observing distinctive signs and trophism of the PF. Muscle relaxation and contraction were observed, as well as the participation of accessory muscles or the paradoxical contraction of the PF musculature. We checked for symmetry the PF and presence of pain. Manometry, (FEPF) of Pelvic Floor – The following measurements were made: strength and resistance of PFM, maximum contraction, maintenance times and the number of effective contraction repetitions.

Results: Fifty-five female (70.5%) and 23 male (29.49%), average age when PPS symptoms started was 42.5 years. The percentage comparison of spontaneous complaints and enquired complaints after relevant explanations showed that, for both genders, there is a higher statistical percentage of enquired complaints than spontaneous ones. Spontaneously, men reported more sexual complaints (57,1%), while women reported more urinary complaints (55,9%). The following signs were observed asymmetry to the external genitalia and PF musculature. Atrophic PF (70.5%) was statistically significant. As for the correlation between manometry and FEPF, the difference was statistically significant. It was observed that the longer the duration of PPS, the greater the amount of symptoms.

Conclusion: Dysfunctions of the PF are frequent in patients with PPS. These results show that, to treat the dysfunctions of the PF in patients with PPS it is necessary refer to a physical therapeutic evaluation and FEPF or manometry.

Summary 57**LATE POLIOMYELITIS IN A SAMPLE OF 791 PATIENTS IN SÃO PAULO - BRAZIL: NATURAL HISTORY THE POLIOMYELITIS AND POST-POLIO SYNDROME****Abrahamo Augusto Juviano Quadros, PT***Universidade Federal de Sao Paulo – Neuromuscular diseases sector, Brazil. E-mail: aajquadros@gmail.com*

Aim and relevance: To describe the natural history of polio and post-polio syndrome (PPS) in patients who had had acute polio at advanced age (after 4 years).

Poliomyelitis in Brazil, India and Africa was characterized as an exclusive infantile disease, without a deviation of higher age at epidemic years, as opposite at other countries of North America and Europe, that considerate the impairment of children after 6 years. The description of the late acute polio (more than 4 years) and its comparison with ordinary age of polio is fundamental for the orientation of specific therapeutic strategies for this patient population.

Method: Patients with PPS with late acute polio history compared with those patients with ordinary age of polio (less than 4 years matched by gender and age).

Results: In 791 patients with PPS, most of them (81.3%) had acute polio before 2 years old; the overall cases presented an average of 1.8 years; the group of Conventional Polio (CP) had a mean age of 1.3 years at acute polio; and the Late Polio group (LP) an average age of 6.8 years. The acute polio was more severe in the LP group (hospitalization = 60.8% and use of invasive ventilation = 16.2%, comparing to group CP, with 43.2% and 9.5%, respectively, $p < 0.05$).

In the LP group, the recovery time was lower than one year and the functional recovery was better (only 10.4% for sequelae in 4 limbs) vs. CP (recovery time of 3 years; residual sequelae in 4 limbs of 39.2%, $p < 0.05$).

The functional stabilization plateau was lower (36 years) in LP, that developed PPS earlier, compared with 39.6 years for CP. The frequency of PPS was higher (82.4%) in LP vs. CP (63.5%) ($p < 0.05$).

The Activities of Daily Living and function are decreased in LP group. From the patients who did sleep tests, 24.1% of LP are using BiPAP and 2.7% are dependent of invasive ventilator. In CP, 18.5% are using BiPAP and nobody uses invasive ventilation.

Conclusion: Patients in the LP group present higher and faster functional recovery than CP, but they have developed PPS earlier than CP. We suggest that it can be happening because of the characteristics of the affected motor unit, the power of reinnervation, the neuronal plasticity and the types of muscle fibers.

Summary 58**FATIGUE IN PATIENTS WITH POST-POLIO SYNDROME IS DETERMINED BY PHYSICAL AS WELL AS PSYCHOLOGICAL FACTORS****Irene Tersteeg, MD, PhD student***Department of Rehabilitation, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands
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Introduction: Fatigue in PPS is often severe, interfering with activities of daily life and leading to restrictions in participation. Greater insight into the factors that contribute to fatigue is needed to design targeted intervention strategies aimed at reducing fatigue in patients with PPS.

Aims: The aim of this study was to identify physical and psychosocial determinants of fatigue and to study the course of fatigue over 5 years in a cohort with patients with the late onset sequelae of poliomyelitis.

Methods and material: Prospective cohort study with 5 measurements over 5 years. Participants were 168 patients with sequelae of poliomyelitis, aged 45–85. Main outcome measure was fatigue assessed with the Fatigue Severity Scale. Potential determinants were perceived physical functioning, bodily pain and mental health assessed with the Shortform 36 (SF-36), co-morbidity assessed with the Cumulative Illness rating scale (CIRS), sleeping disorders determined with the Nottingham health profile (NHP), extent of paresis measured according the Medical Research Council Scale, social support measured with the social support scale and coping measured with the Coping Inventory for Stressful Situations. A model was composed using multivariate linear regression analysis performed with generalized estimating equations.

Results: During the 5-year follow-up there was no significant change in fatigue. Reduced physical functioning, higher levels of bodily pain, more psychological distress, reduced sleep quality and higher task-oriented coping were independently associated with fatigue. Muscle strength was not associated with fatigue, but was strongly associated with physical functioning.

Conclusions: Fatigue is severe and persistent in patients with LOSP due to physical and psychological factors, which has implications for counselling and treatment. In addition to the commonly applied interventions targeting physical aspects, psychological interventions are a potential area for reducing fatigue.

Summary 59**CONFIDENCE IN THE FUTURE AND HOPELESSNESS – EXPERIENCES IN DAILY OCCUPATIONS OF IMMIGRANTS WITH LATE EFFECTS OF POLIO****Iolanda Santos Tavares, OT^{1,2}***¹Institutionen för Neurovetenskap och Fysiologi/Arbetssterapi and ²Fysioterapi, Göteborg, Sweden
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Introduction: Globalisation implies an increase in migration. The growing number of immigrants has brought about a change in the Swedish population. Studies have shown that immigrants in Sweden seem to have poorer health than native-born Swedes. Being an immigrant and having a disability is sometimes described as “double vulnerability”. The proportion of immigrants in the population that has suffered polio is rising.

Aims: To explore and describe how immigrants with late effects of polio experienced their daily occupations.

Methods and material: The experiences were explored by interviews with 12 immigrants with late effects of polio, men and women (20–42 years), from Eastern Africa. Data analysis was carried out according to grounded theory. Structured interviews regarding demographic data were also included.

Results: Experiences in daily occupations affected the participants' view of the future which in turn was influenced by the participants' conception of occupational self. The large variation in experiences implied that the participants had confidence in the future and a feeling of hopelessness. This was dependent upon their possibility to reach the goal of participating in daily occupations like everybody else. The five categories influenced the participants' occupational self: rootedness in society, others' estimation, treatment by others, belonging to the social networks and the process of change in life. The social environment played an important role in determining how the participants experienced their daily occupations.

Conclusions: The participants' experiences in daily occupations were highly varied and could not be seen in isolation; consequences of their disability and migration interact. The study showed that complexity in the daily life among immigrants with disability; requires an individual treatment. Besides individual treatment, the study points to a need for consideration of differences in cultural background, including therapists own cultural lens through which they perceive and understand people.

**REHABILITATION
(PLENARY)**

FRIDAY SEPTEMBER 2, 2011 AT 10.30–12.00

Summary 60

REHABILITATION IN A PUBLIC HEALTH PERSPECTIVE

Claus Vinther Nielsen, MD, PhD, Ass. Professor, Head of Research

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The Rehabilitation concept, The Rehabilitation Forum in Denmark and how you recommend that the rehabilitation process is organized for chronic disabled persons.

Elderly people constitute a still greater part of the population and an increasing number of the population has to live with the consequences of chronic illness. The illusion of being able to solve the problems through biomedicine alone has been shattered. Rehabilitation is not a concept in Danish legislation. Denmark has during more than hundred years moved into a welfare state characterized by high quality of life and life expectancy. The Danish legislation has in the period focused much on how ill citizens in spite of the disease can maintain the highest possible activity and participation and an autonomous and meaningful life. Nevertheless, today, still between 10 and 12% of the population, find it difficult or very difficult to manage everyday life following chronic illness. These are citizens who besides an overloaded life costs society great resources, because the citizen expects that the health services (GP's and hospitals) can solve their problems with functioning in daily life. This is unfortunately not the case. The health services focus on symptom relief and do not have focus on and knowledge how to live with symptoms. Over the past 10 years, health-care professionals and professionals from social services in particular inspired. The WHO developed the first Danish rehabilitation definition. Over the past year, a similar group across professions and public sectors identified the major challenges for the Danish rehabilitation. The challenges are described in 74 stories from practice. Work is now until November this year to formulate recommendations to enable rehabilitation in Denmark moves from concept to practice. The speech will focus on the definition, challenges and recommendations. And do we have evidence that it will work according to the intention?

Summary 61

INTERDISCIPLINARY TEAMWORK

Jan Lexell, MD, PhD, Professor of Rehabilitation Medicine, Medical director

Department of Health Sciences, Lund University; Department of Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden. E-mail: jan.lexell@skane.se

Post-polio is characterised by new symptoms that often lead to limitations in the performance of daily activities, such as housework, leisure activities and work, which impacts on perceived participation in society and life satisfaction. As with many life-long disabilities, people with post-polio benefit from being admitted to a team specialised in the condition. In the EFNS Guidelines on post-polio it is stated that group training, regular follow-up and patient education are useful for the patients' mental status and well-being and give a more positive experience of self. This indicates that people with post-polio, with the support of rehabilitation professionals, go through a process of change leading to a better life. These professionals work as a team. A rehabilitation team, comprising a physician, occupational therapist, physiotherapist and social worker, work in close collaboration with the person and his or her family to achieve the desired goals and optimal outcome. This interdisciplinary teamwork has a common goal: to reduce self-perceived disability by providing a variety of interventions and thereby maximize each individual's physical, mental and social potential. The teamwork is also facilitated by a clear strategy, starting with an assessment where the nature and extent of a disability is confirmed. Based on this assessment and the individual's own needs, rehabilitation goals are defined by the individual in close cooperation with the team. Another important component of the interdisciplinary teamwork is the rehabilitation plan. In modern rehabilitation, the plan is based on the International Classification of Functioning Disability and Health (ICF) and comprises three parts: the assessments (focusing on the consequences of post-polio), the goals (focusing primarily on activity and participation) and interventions, and the continuation following the rehabilitation period. To succeed, the team should also let the person with post-polio try different aids and compensatory techniques, and provide other necessary medical and non-medical interventions. Recent research has shown that interdisciplinary rehabilitation can support persons with post-polio to adopt self-management strategies and thereby experience a positive turning point in life. During such a process of change that forms the turning point, they can acquire new skills, and experience considerable positive changes in their management of daily activities and in their view of their late effects of polio, their future and their self.

Summary 62**THE VALUE OF INVESTIGATING PATIENT PERSPECTIVES: FITNESS AND COGNITIVE BEHAVIOURAL THERAPIES FOR FATIGUE AND ACTIVITIES IN POST-POLIO SYNDROME (FACTS-2-PPS)****Karen Schipper¹; Tineke A. Abma¹; Frans Noller²**¹VU Medical Center, EMGO Institute, Department of Medical Humanities, and ²Department of Rehabilitation, University of Amsterdam, Academic Medical Center, Amsterdam, The Netherlands. E-mail: k.schipper@vumc.nl

Investigating the perspectives of patients is important to achieve meaningful research outcomes for patients and to enhance the implementation of results. The experiential knowledge of patients has an added value in completion to the knowledge of professionals since patients bring in an unique perspective due to their illness. Patients should furthermore have the right to become involved in research because they will be affected by the outcomes.

Therefore, the investigation of patient perspectives is included in the FACTS-2-PPS-trial, which investigates the efficacy of exercise and cognitive behavioural therapy on fatigue, activities and quality of life (QoL). The study is aimed at investigating how patients and therapists evaluate the effects of the intervention and how patients experience the study. A responsive methodology consisting of interviews and focus-groups is followed to get insight in the experiences of the stakeholders.

In this presentation preliminary findings of the responsive methodology will be presented just as the value and ways of incorporating the perspectives of patients in research. The first interviews resulted into information about how patients experience the study and the interventions and their effects. Patients mentioned first of all concerns regarding the method of communication used by researchers to inform about the inclusion-decisions and about the confronting nature of items in questionnaires. Patients furthermore mentioned how they may occasionally adjust their answers in order to fulfil the inclusion criteria. Both interventions are among others, aimed at reducing fatigue. Patients mention however mainly other effects such as a better self-confidence and self-acceptation.

The preliminary findings have provided insights into how the research process can be improved and how patients experience the interventions. Patient perspectives may assist with the interpretation of the results and identify avenues for improving future interventions and implement these interventions.

Key points:

- The perspectives of professionals and patients can be seen as complementary to each other.
- Qualitative methods that start from a patient-centred approach and that leaves enough space for the experiences of patients could be combined with quantitative methods in order to improve the research process, its outcomes and the implementation of the outcomes.

Summary 63**MY LIFE WITH POLIO****Sylvi Salomonsson, Secondary School Teacher and Polio Survivor**

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I was nine months old when I got polio in 1952. My right leg is shorter than my left, my right foot is one shoe size smaller and I have fewer muscles in my right leg. Nevertheless, I have lived an active life enjoying dancing, swimming and skiing. I compensated my right leg with my left. It was not until I was about 50 that I started to feel tired. Then I couldn't keep my balance and I fell quite often. My children thought it was embarrassing. The pain came. I got even more tired and I couldn't walk up the stairs in my own house. I realized I had to see a doctor. Immediate sick-leave half time was the ordination and then a visit to the Polio Clinic at Orup in the south of Sweden. I spent two weeks at the "Polio School", I learnt a lot about the Post-Polio Syndrome and how to cope with my difficulties. But most important I accepted my new diagnosis: Post-Polio.

Today I save my strength in order to manage a full day. I always rest in the middle of the day. I drive my car to work, this way I have the energy to walk in and between classrooms. I also drive to the shops and I always use a trolley because it relieves the pressure.

I do physical training once a week in a warm water pool, it is good exercise. Once a week I do pilates which is all about knowledge of the body and correct breathing techniques and the program is adjusted to our group. I use a chair to get up from the floor. I also have my own training program that I got from my physiotherapist at Orup. When I want to take a walk I use my walking sticks. I know where the next bench is, I rest in time, I listen to my body and I know not to overdo it.

I used to think I could do everything but now I have learnt to ask for help. I used to be in a hurry all the time. Today I take my time, it works! Planning is important. Plan for rest, plan for exercise, learn to save energy and learn to say no! This is my new life, it is good!

AWARENESS OF POST POLIO IN THE POLITICAL AND SOCIAL SYSTEM (PLENARY)

FRIDAY SEPTEMBER 2, 2011 AT 13.00–15.00

Summary 64

POST POLIO SYNDROME POLICY IN THE EU

**Holger Kallehauge, Retired High Court Judge,
President of The Danish Society of Polio and
Accident Victims
Denmark**

How shall we in The European Union (EPU) enhance and work for:

- Research in Post-Polio.
- Adequate rehabilitation, training and treatment to all Polio survivors.
- Development aid to Polio survivors in poor countries in the third world.

How shall we make best use of the UN Convention of December 13th 2006 about the rights of persons with disabilities (CRPD) to forward the three above mentioned goals at a national, European and global level?

We need to agree on an EPU strategy for developing a programme leading to a fulfillment of these three goals:

- A research programme.
- A scientific post-polio committee has to be established in the EU. This committee shall be a coordinator for research activities in the field of post-polio. The committee shall act as a center, where all medical knowledge about post-polio shall be registered in a database at disposal for all doctors and other health personal and to the public as such.
- A post-polio rehabilitation programme.

EPU shall adopt a plan of action leading to developing of a standard rehabilitation programme for Polio survivors.

The goal is to secure, that such a rehabilitation programme primarily is made well known and accepted by doctors, physiotherapists and other health personal in all EU member states but also realized in practice so that all polio survivors have access to such a rehabilitation programme.

It is also needed to identify at least one national rehabilitation center for Polio survivors in each member state hopefully as a special clinic or unit at a major university hospital.

An international development aid programme for Polio survivors in the third world.

In the UN Disability Convention CRDP article 32 one find a rule about international cooperation. Implementation of this rule for Polio survivors ought to be an important goal for the EU. EPU should take this up lobbying for our brothers and sisters with Polio impairment in developing countries giving them better and more equal opportunities in their home countries. Obviously they need support much more than we do in the EU.

EU is one of the major global international donors. The resources are available, but EPU has to influence the distribution, so that Polio survivors are given the priority and share the need of EU-development aid.

Summary 65

DISABILITY IN THE POLITICAL ARENA

**John Richard McFarlane, PhD, FIMS, MBIM,
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Disability has been with us since the dawn of time and when language evolved mankind has argued, or debated to put it politely. Debate and difference is at the heart of politics as it is understood in the modern era therefore why should disability and politics not go together.

Even so, disability and politics seem strange bedfellows to many, but should it be so, those with disabilities represent a cross section of society. Many of the pressures exerted by disability groups and activists have achieved change faster and more comprehensively than through conventional routes.

However, there is a very distinct difference between disability in the political arena and politicians with disabilities, they are not necessarily, nor very often, the same thing. Take probably the most famous disabled politician of the last century, Franklin D. Roosevelt, few in the world let alone the USA knew that he was a polio survivor. He fought and won on his abilities, not his disabilities, yet there was an element of disability in the political arena within the family – his wife Eleanor. She was one of the most influential women of her time in promotion of these issues, and this still resonates today.

Another true but sad fact is that some of the most political acts that have benefited those with disabilities have arisen from conflict. Think back to the returning veterans from the major wars of the 20th century, starting with World War I and accelerating through to the returning veterans of the Vietnam conflict and those of today from wars around the globe. They took to the streets and turned disability into a political hot potato, they could not be ignored – they were VOTERS, they had rights and expected them to be respected.

Why is it that disability can play such an important part not just in the political arena but also in mainline politics, simply those with disabilities know what they want. The “politicians” suddenly woke up to the fact that one in four families have someone within their close circle who have a disability, at least 15% of the population of each country within the United Nations are disabled and expect to participate fully in society, including politics.

Summary 66

COST EFFECTIVENESS

**Kjeld Møller Pedersen, Health Economist
Denmark**

No abstract available.

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POSTER PRESENTATIONS AT POST POLIO CONFERENCE IN COPENHAGEN

Summary 67**ANALYSES OF SLEEP CHARACTERISTICS IN POST-POLIO SYNDROME PATIENTS****Tatiana Mesquita e Silva, PT***Universidade Federal de Sao Paulo, Neuromuscular diseases sector, Brazil. E-mail: tatimsilva@gmail.com*

Introduction: A study of 60 patients with post-polio syndrome (PPS) in 2010 (1) (ages 32 to 59 years) analyzed their sleep patterns. Median male age was 47, median female age 48. All patients met the PPS criteria set at the 2001 conference. Patient evaluations were made using scales for fatigue severity; Epworth sleepiness scale; a visual analogue scale for pain; and an exam at a local sleep institute. Sleep parameters were correlated to pain, sleepiness, and fatigue. Observations: high sleep latency and increased arousals reduced sleep efficiency. Higher index numbers for apnea and hypopnea (AHI) and PLM were noted. No abnormalities were seen in oxygen saturation, carbon dioxide levels, respiratory rates, or heart rates.

Conclusion: The newly observed PPS patient sleep disturbances were isolated symptoms caused by intensive dysfunctions of surviving motor neurons in patients' brainstems. Abnormal dopamine production could also be inferred in these findings.

In 2011, findings in our double-blind (as yet unpublished) study noted effects of MIG3 bioceramic mattresses on PPS patient sleep quality.

Objective: Assessment of four week use of MIG3 bioceramic mattresses and PPS patient improvements in pain; daytime sleepiness; daily activities; quality of life; and sleep quality.

Methods: Random; controlled; and double-blind. Two groups of PPS patients were compared over four weeks. One group used mattresses lined with MIG3 bioceramic (TG) ($n=25$), and a control group (CG), used common mattresses i.e. no MIG3 linings ($n=27$). Patient evaluations used the following scales and exams: Epworth sleepiness scale; a sleep exam the night before the first use of the MIG3 mattress and another the night after 4-weeks use of MIG3 mattress; McGill pain questionnaire; analogue visual pain scale; Barthel index for daily activities; and WHOQOL-BREF for life quality.

Observations: After 4 weeks MIG3 patients had reduced sleep latency (28.2 ± 15 vs. 58.4 ± 45 minutes, $p=0.003$), reduced duration of stage II ($p=0.04$), and improved life quality (30.2 ± 8.4 vs. 24.1 ± 9.6 , $p<0.05$), and patients presented improved pain scores ($p=0.001$).

Conclusion: After 4 weeks MIG3 bioceramic mattress use PPS patients afflicted with poor sleep quality showed marked sleep quality improvement, decreased pain, and dramatic improvement in life quality.

Reference:

1. Silva TM, Moreira GA, Quadros AAJ, Pradella-Hallinan M, Tufik S, Oliveira ASB. Analysis of sleep characteristics in post-polio syndrome patients. *Arq Neuropsiquiatr* 2010; 68: 535–540.

Summary 68**COMPARISON OF SELF-REPORTED FATIGUE IN POST-POLIO SYNDROME PATIENTS AND AGE-MATCHED CONTROLS****Charlotte Lucy Taylor, Honorary Research Assistant**
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Introduction: Post-Polio Syndrome (PPS) is characterized by the onset of new symptoms such as muscle weakness and extreme fatigue, many years after the original polio infection (Dalakas, 1995). When compared to controls and patients with other medical conditions, people with PPS reported higher levels of fatigue, using the Fatigue Impact Scale (On, Öncü, Atamaz & Durmaz, 2006).

Aims: For the current study a new draft questionnaire was designed to measure fatigue in patients with PPS. It was hypothesized that PPS patients would again show higher levels of fatigue than age-matched controls.

Methods and material: Initial interviews were conducted with patients with PPS and then transcribed. The transcripts were used to derive 62 statements about fatigue which formed the new fatigue questionnaire. When completing this questionnaire the participant had to indicate how often each statement applied to them. The scores were added to form a fatigue score on a scale of 0–186.

Patients were requested to fill out the questionnaire if they conformed to Halstead and Rossi's (1985) definition of PPS: a confirmed history of polio and reported new muscle weakness and fatigue after a period of at least 15 years of stability. Controls were mainly friends and family of patients.

Results: Response rates were 283 out of 319 (89%) for PPS patients, mean age of 66.6 years (SD=8.2), and 131 out of 206 (64%) for controls, mean age of 62.9 (SD=8.5). Within the control population 11 respondents reported having a medical condition and 3 reported having a disability (4 of these respondents reported having both). For the analysis participant data was excluded if there were 3 or more questions left blank. Therefore, data for 10 PPS patients and 7 controls were excluded from the analysis. The analysis showed that PPS patients reported a higher level of fatigue ($M=129.83$, $SD=30.14$) than controls ($M=30.71$, $SD=32.75$).

Conclusions: In summary, it appears that people with PPS have higher levels of fatigue than age-matched controls. This study forms the basis for refining a new patient reported outcome measure which is specifically designed and validated for PPS fatigue.

Summary 69**NEW MUSCLE WEAKNESS IN THE SUBCLINICALLY INVOLVED LIMBS IN PATIENTS WITH POLIOMYELITIS****Arzu Yagiz On, MD, Professor of PMR***Ege University Medical Faculty, Department of Physical Medicine and Rehabilitation, Izmir, Turkey**E-mail: arzu.on@ege.edu.tr*

Introduction: The limbs are affected nonuniformly in poliomyelitis. Polio affection of the limbs can be classified according to the clinical history, examination and EMG findings by using National Rehabilitation Hospital Post-polio limb classification system, in order to determine the management strategies.

Aims: To classify polio affection of the limbs in our patients who admitted to our post-polio clinic, according to the clinical history, examination and EMG findings.

Methods and material: We investigated systematically 448 limbs of 112 patients with a history of poliomyelitis. Detailed clinical histories of the patients were taken. Muscle strengths were measured in all limbs of the patients. Electromyographic investigations were performed in selected proximal and distal muscles in the limbs.

Results: The limbs were classified as having no clinical polio in 40%, subclinical polio (without subjective muscle weakness, normal muscle strength, old polio findings in EMG) in 14%, stable polio (without new muscle weakness, reduced muscle strength, old polio findings in EMG) in 11%, unstable polio (with new muscle weakness, reduced muscle strength, old polio findings in EMG) in 14% and severely atrophic (severe muscle weakness, severely reduced muscle strength, no activity or severely reduced recruitment in EMG) in 10% of the limbs investigated. EMG studies indicated subclinical involvement in 112 out of 292 limbs considered not to be affected originally (36%) and in 48 out of 108 limbs that developed new muscle weakness (44.5%). In total, 11% of the limbs have subclinical involvement and developed a new muscle weakness.

Conclusions: The limbs with subclinical involvement may develop new muscle weakness in patients with poliomyelitis. Therefore, this class should be added to the classification systems regarding polio affection of the limbs.

Summary 70**RELATIONSHIP BETWEEN LOWER LIMB MUSCLE STRENGTH AND GAIT PERFORMANCE IN PERSONS WITH POST-POLIO SYNDROME****Ulla-Britt Flansbjer, RPT, PhD^{1,2}; Christina Brogårdh, RPT, PhD^{1,2}; Jan Lexell, MD, PhD^{1,2}***¹Department of Rehabilitation Medicine, Skåne University Hospital, Lund and ²Department of Health Sciences, Lund University, Lund, Sweden**E-mail: ulla-britt.flansbjer@med.lu.se*

Introduction: A common impairment in persons with post-polio syndrome (PPS) is muscle weakness in the lower limb, which often impedes on the ability to walk in various environments. For the planning of appropriate rehabilitation interventions, we need thorough understanding of the relationships between lower limb muscle function and walking ability in persons with PPS.

Aims: The aim of this study was to determine the relationship between lower limb muscle strength and gait performance and to what extent it contributes to reduced walking ability in persons with PPS.

Methods and material: Fifty-six community-dwelling ambulant individuals with clinically verified PPS were included in the study (27 men and 29 women; mean age 62 years). Isokinetic concentric knee extension and flexion strength was measured at 60°/s and ankle dorsiflexor strength at 30°/s in a Biodex dynamometer. Gait performance was assessed with the *i*) Timed “Up & Go” (TUG); *ii*) 10 m Comfortable Gait Speed (CGS); *iii*) 10 metres Fast Gait Speed (FGS); and *iv*) 6-Minute Walk (6MW).

Results: There was a significant correlation ($p < 0.01$) between knee muscle strength and gait performance for both the less-affected and the more affected lower limb. Knee muscle strength explained 15% to 55% of the variance in gait performance. For the less affected lower limb there was a significant correlation between ankle dorsiflexor strength and gait performance ($p < 0.01$; $n = 51$) but for the more affected lower limb only for Fast Gait Speed ($p < 0.05$; $n = 30$).

Conclusions: Knee extensor and flexor muscle strength are strong predictors of walking ability in persons with PPS and can explain up to 55% of the variance in gait performance whereas ankle dorsiflexor muscle strength is a more moderate predictor.

Summary 71**RELATIONSHIPS BETWEEN OBJECTIVELY AND SUBJECTIVELY ASSESSED GAIT PERFORMANCE IN PERSONS WITH POST-POLIO SYNDROME****Christina Brogårdh, RPT, PhD, PT***Department of Rehabilitation Medicine, Skåne University Hospital, 221 85 Lund, Sweden**E-mail: christina.brogardh@skane.se*

Introduction: A common impairment in persons with post-polio syndrome (PPS) is muscle weakness in the lower limb, which often impedes on the ability to walk in various environments. In a rehabilitation perspective, it is of interest to assess gait performance not only objectively, but also subjectively to be able to evaluate if the interventions have had any impact on the person's ability to perform daily activities. Several instruments are used to assess gait performance, but our knowledge of the relationship between them is limited.

Aims: To assess the relationship between objectively and subjectively assessed gait performance in persons with PPS.

Methods and material: Sixty persons (29 men, 31 women, mean age 61 years) with clinically verified PPS were included in the study. Gait performance was objectively assessed using the: *i*) Timed "Up & Go" (TUG); *ii*) 10 m Comfortable Gait Speed (CGS); *iii*) 10 m Fast Gait Speed (FGS); and *iv*) 6-Minute Walk (6MW). These tests have previously been shown, in our research group, to be highly reliable in individuals with PPS. Self-perceived walking ability was evaluated using the Swedish version of the "Walking Impact Scale" (Walk-12). The participants rated on a five-point Likert scale (from not at all to extremely) their self-perceived limitations when walking and performing ambulatory movements, over the past two weeks.

Results: The Pearson correlation coefficient revealed that there were significant correlations between Walk-12 and all the objective gait performance tests ($r=0.52$ to 0.67 ; $p<0.001$).

Conclusions: This study indicates that objectively measured gait performance is strongly associated with subjectively assessed gait performance and that subjectively assessed gait performance, using the Walk-12, can be used to evaluate walking ability in persons with PPS.

Summary 72**THE WHOQOL-BREF PROVIDES A VALID MEASURE OF QUALITY OF LIFE IN POST-POLIO SYNDROME****Ian Pomeroy, PhD, Neurologist***Walton Centre for Neurology & Neurosurgery, Lower Lane, Liverpool, UK**E-mail: Ian.pomeroy@thewaltoncentre.nhs.uk*

Introduction: The WHOQOL-BREF was developed as a measure of quality of life (QOL) which is applicable cross-culturally. The scale provides a measure of QOL across four separate health domains; physical health, psychological, social relationships and environment.

Aims: We aimed to evaluate the validity of the WHOQOL-BREF in PPS by testing it for fit against the Rasch model.

Methods and material: The scale was posted to 319 people with post-polio syndrome (PPS) recruited from a suprar-regional clinic and through the British Polio Fellowship. Response rate was 271 (85%) with a mean age of 66.7 years ($SD=8.15$), 64% were female. Data was analysed in an iterative procedure which examined evidence of misfit or violation of the assumptions of the Rasch model.

Results: The social relationships domain fitted the Rasch model (Chi Square $p=0.19$) but reliability was low (Cronbach's $\alpha=0.69$) and there were insufficient items to test the assumption of unidimensionality. Reliable, unidimensional solutions were found by combining thresholds and items for the psychological domain ($p=0.19$, t -test 4.8%, $\alpha=0.78$) and environmental domain ($p=0.48$, t -test 6.4%: CI 3.4-9.4, $\alpha=0.81$). A solution for the physical domain was achieved ($p=0.72$, t -test 4.2%, $\alpha=0.78$) but required the scale to be split for differential item functioning by age group. An overall measure of health status which combined the physical, psychological and social domains was validated ($p=0.80$, t -test 4.6%, $\alpha=0.81$).

Conclusions: These data do not demonstrate reliability or unidimensionality of the 3 item social relationships domain but other domains of the WHOQOL-BREF can be adjusted to meet the assumptions of the Rasch model in a population of PPS patients. The physical health domain required adjustments in scores to compare QOL across different age groups. In addition, this data validates the use of an overall measure of QOL by combining the physical, psychological and social domains of the WHOQOL-Bref.

Summary 73**POST-POLIO SYNDROME AND AMYOTROPHIC LATERAL SCLEROSIS - SIMILARITIES, DIFFERENCES AND DIAGNOSTIC DILEMMAS**

Ewa Matyja, MD, PhD; Milena Laure-Kamionowska, MD
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Post-polio syndrome (PPS) and amyotrophic lateral sclerosis (ALS) are neurodegenerative disorders characterized by motor neurons (MNs) loss in the spinal cord, brain stem and motor cortex. The distinction between PPS and ALS bears important prognostic implications as ALS is a rapidly progressive lethal disease with a low survival rate, whereas PPS is regarded to be a slowly progressive syndrome. Both these motor neuron diseases (MNDs) still remain a challenge for clinical and scientific community and require better understanding of their etiology and treatment efficacy.

The patients with post-polio muscular atrophy (PPMA) develop clinical symptoms similar to the onset of ALS with weakness and muscular atrophy due to upper and/or lower MNs involvement, occasionally accompanied by respiratory or swallowing problems. Although the neuropathological features consisting of MNs loss in both PPS and ALS are similar, the histopathological details are different. Neuropathology in PPS has been reported in a few autopsy findings and revealed MNs loss of anterior horn of the spinal cord with gliosis and inflammatory B cells infiltrates, without corticospinal tracts involvement. In human sporadic and familial form of ALS a variety of neuronal inclusions are observed as Lewy-like, Bunina bodies and hyaline or ubiquitin-immunoreactive inclusions, which are not typical for PPS. The signs of inflammation in ALS cases were reported only sporadically.

The etiopathogenesis of ALS and PPS is not fully understood and an involvement of different pathological factors related with progressive MNs stress, accompanied by age-dependent risk factors ought to be considered. Moreover, about 1% of patients with a history of paralytic polio have been reported to develop ALS as coincidental findings. The histopathological diagnosis in such cases is very difficult as features of PPS and/or ALS are developing on the background of primary spinal lesions of poliomyelitis.

The diagnosis of PPS and ALS is based on exclusion clinical criteria since there were not specific tests and biomarkers for confirmation of diagnosis. The basic principle of management address to both PPS and ALS patients is mostly supportive and require individually tailored training programs and lifestyle modification. However, due to the differences in the rate of natural progression of these MNDs, the management in ALS patients is more aggressive and include respiratory assistance and supplemental nutrition at early stages of the disease.

Key words: PPS and ALS; differential diagnosis.

Summary 74**VALIDITY AND RELIABILITY OF THE TURKISH VERSION OF FATIGUE SEVERITY SCALE AND FATIGUE IMPACT SCALE FOR POST-POLIO SYNDROME**

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Introduction: Fatigue Severity Scale (FSS) and Fatigue Impact Scale (FIS) have been used to describe fatigue in polio survivors. However, validity and reliability of Turkish translation of these scales have not been determined so far.

Aims: To adapt FSS and FIS into Turkish and then to test its reliability and validity in a group of patients with post-polio syndrome.

Methods and material: The FSS and FIS were translated into Turkish by the forward and backward translation procedure and then administered to 48 patients who had diagnosed as post-polio syndrome. The reliability studies were assessed by test-retest reliability with intra-class correlation coefficient (ICC) and internal consistency (Cronbach's alpha). Construct validity was assessed by correlating the FSS and FIS with dimensions of Nottingham Health Profile (NHP), 100 mm visual analog scale (VAS) for pain, fatigue, weakness and muscle cramps, gait velocities and total limb muscle strengths.

Results: Reliability of the adapted versions of the scales was satisfactory with high Cronbach's alpha values (0.89, 0.88, 0.86 and 0.89 for FSS, FIS cognitive, FIS physical, FIS social, respectively). ICC values were also high in all domains with higher coefficients than 0.90 (ranged from 0.97–0.99). Significant high correlations were obtained between FSS and the other clinical measurements. While there were moderate correlations between FIS physical and NHP energy scores, and high correlations between cognitive and social subgroups of FIS and NHP social, no correlations were found between VAS for fatigue, FSS and FIS.

Conclusions: Turkish version of FSS is a reliable and valid instrument for measuring fatigue in PPS. Although Turkish version of FIS is a reliable instrument for this purpose as well, it has a limited validity.

Summary 75**CONCEPT OF AN INTERDISCIPLINARY POLIO MODUL PROGRAMME AND THERAPY FOR POLIO****Axel Ruetz, MD***Ltd. Arzt Abteilung für Konservative Orthopädie und des Poliozentrums, Katholisches Klinikum, Koblenz, Germany*

About 70,000 German survivors of polio are attended to an acute hospital with an attached ambulance in Koblenz. It is typical of the German health system that diagnosis and acute intervention with stationary indications are adducted in hospitals; rehabilitations of pre-treated and pre-diagnosed consequent conditions of poliomyelitis are adducted in rehabilitation clinics. This institution for secondary diseases after paralytic polio process has been admitted by the Ministry of Health for the first time and is unique in Germany. The concept of acute treatment is carried out modularly and interdisciplinary, depending on the patients' needs (400 affected per year at the time being).

Module A is supposed to diagnose and treat loss of function, leftover capacities and the prognosis of post-polio syndrome. Pneumologically, examinations of lung function, respiratory strength and sleep take place, where required with ventilation supply.

In order to make a diagnosis and to acknowledge the stadium, imaging methods, especially lavish MRT examinations, CT and functional X-rays, are being used.

Neurological examinations with electrophysiological results are being applied for diagnosis of exclusion and of process.

Module 1 serves for orthopaedic treatments of specific and painful decompensations with PPS. Orthopaedically, the classification of function and stadium is being accomplished through measurement of efficiency in following, function improving activities such as interventional pain therapy- juxtaspinal or at the joints-, orthotic supply, physiotherapeutic or medical drug treatment.

Module 2 is supposed to achieve function improvements of the specific handicaps after Polio and with PPS.

Module 3 will help in case of failure of conservative orthopaedic therapies with adverse effect of functions and painful diseases under consideration of special anaesthesiologic allowance and operative risks by operations at soft parts, bones and joints.

The function of Module 4 is to recondition Polio consequent conditions – in connection with Module A and Module 1–3 and in form of a stationary subsequent measure in a clinic which is certified by the Bundesverband Polio e.V..

The special ambulance of the Polio Centre at the Catholic Clinic is a first-contact and consequent supply institution with free access like public health, which conducts around 1000 consultations per year as well as 150 first investigations and ambulant examinations.

Temporally and interdisciplinary, stationary examination and treatment algorithms are constructed as modules in range, so that uniform and programmatic examinations and treatments for Polio affected exist as stationary, primary examinations and treatments in Module A.

Conclusions: For the first time, we present the concept of an interdisciplinary Polio Module Programme for PPS patients in Koblenz, Germany.

Summary 76**BENEFITS AND TECHNIQUES OF AQUATIC THERAPY****Cynthia Henley, PT; Kathryn Wollam, PT***University of Miami Post-Polio Clinic, USA. E-mails: cynthiahenley@bellsouth.net; katwollampt@yahoo.com*

Aquatic therapy was utilized during the recovery phase from acute polio. Its benefits, precautions and techniques, and the challenges and guidelines of exercise for polio survivors are discussed. Aquatic exercise offers unique physical and physiological benefits, in addition to general exercise benefits. Water exercise supports the body and reduces joint stress, offering the ability to improve flexibility, strength, aerobic condition and function.

Exercise can be a challenge for individuals with a history of polio. Balance between overuse and disuse must be achieved. An exercise program that is tailored to the individual's specific muscle test is essential to be safe and effective. Extremities used in strengthening exercise must be able to move through complete range of motion against gravity. Water can facilitate a workout that can be tailored to each person's strength. Polio survivors must avoid excessive fatigue with any exercise.

Simply being immersed in water has a positive therapeutic effect on our bodies. These physical properties of water make exercise less difficult and painful, while increasing its effectiveness for polio survivors.

Buoyancy is explained by Archimedes' Principle. When a body at rest is immersed in a fluid, it experiences an upward thrust equal to the weight of the fluid displaced. Buoyancy of water provides support while decreasing gravitational forces on weak limbs, offering less strain to move underwater.

Pascal's Law defines hydrostatic pressure as fluid pressure exerted equally on all surface areas of an immersed body at rest at a given depth. Hydrostatic pressure helps with circulation, cardiac efficiency and distal swelling, but can be stressful to those with respiratory involvement if fully immersed.

Relative density is the relation of the mass of an object to the mass of an equal volume of liquid at standard temperature and pressure. If an object is denser than water, it will sink. Dense lean and muscular limbs will sink; those with more adipose tissue, swollen or paralyzed extremities float.

Fluid resistance is the force that opposes the motion of an object through a fluid. Aquatic therapy supports while also resisting movement, providing a perfect environment for balance exercise.

Turbulence, the random motion of the water as it responds to a disturbance, provides therapeutic benefits of massage and resistance.

A pilot project to validate the effectiveness of aquatic exercise for polio survivors will be conducted by the authors. Standard functional, strength, fatigue and quality of life scales will evaluate the benefits of the program.

Summary 77

DISABILITIES AND WORKING SITUATION OF IMMIGRANT WITH POST-POLIO SYNDROME

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Introduction: In our clinic nearly all of the younger patients with post-polio syndrome were born in other countries than Sweden. This group of patients needs to be introduced to a new society and to be adapted to a new life and work. In order to give more appropriate treatments and help to these patients, we analyzed the grade of these patients' disabilities and their working situations.

Aims: To analyze the patients' disabilities and their working conditions in order to give the patients more appropriate aids.

Methods and material: 149 immigrant patients from Africa, Asia, Europe, Middle East and South America were included. Patients answer of a survey, results of muscle strength test and walking tests were analyzed.

Results: The average age was 35.9 years for woman and 39.8 years for men. Most of the patients had mild to moderate disabilities and nearly all of the patients experience pain. These patients had about 20% decreased self-selected walking speed comparing with the control group. About one third of the patients were employed while women had a higher rate of sick leave than men.

Conclusions: It appears that this group of patients had obvious limited physical activities and participation due to their disabilities. They may need more information about the disease and how to use the assistive devices. More effective treatments of pain could improve their function and life qualities. A further study in comparing the immigrant patients with the patients born in Sweden would be necessary to give a more clear picture of the patients' situation.

Summary 78

EXPERIENCE WITH YOUNGER PATIENTS IN A POST-POLIO CLINIC: A CASE SERIES

Judith Glaser, DO, Physician

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Introduction: As the polio population ages, the mean age of patients seen in our clinic has increased. At the same time, we are also seeing a younger cohort of survivors.

Case Description: Between 2009–2010, we evaluated 20 patients under the age of 50 with a past medical history of acute paralytic poliomyelitis (APP) as a child. The mean age was 39.5 (range: 29–47) representing 7.7% of all patients seen. APP occurred at a mean age of 16 months between the years 1960 and 1984 in their home countries. Ninety-five percent immigrated to the United States (USA). Thirteen presented with complaints of new weakness, 14 with fatigue and 12 with pain consistent with post-polio syndrome (PPS). One was pregnant, 16 are married and 12 have 1 or more children under the age of 10.

Results: There are two cohorts seen in our clinic: an older group who typically contracted APP during the mid-20th century epidemics in the USA and a younger group who had polio as infants in developing countries and then immigrated here as children or young adults.

Conclusions: Despite the steady decline in the number of survivors from the mid-century epidemics in the USA, it is estimated that there are between 10 and 20 million polio survivors worldwide. In our clinic, 95% of the younger polio patients have immigrated to the US from polio endemic countries. In contrast to the typical older patient, the younger polio survivors present a different and challenging mix of issues such as schooling, work, and raising a family. While polio patients are getting older, there is a younger cohort of immigrants, especially in metropolitan areas, who will continue to need post-polio care from physiatrists well into the future.

Summary 79**PRESCRIPTION OF AND SATISFACTION WITH THE USE OF LOWER LIMB ORTHOTIC DEVICES IN PERSONS WITH POST-POLIO SYNDROME****Christina Espelund, RPT, MSc, PT***Department of Rehabilitation Medicine, Skåne University Hospital, Lund, Sweden**E-mail: christina.espelund@skane.se*

Introduction: Persons with post-polio syndrome (PPS) can experience new or increased muscle weakness, fatigue and pain. This can affect their ability to walk and perform activities of daily living. One part of the interdisciplinary rehabilitation process for persons with PPS is to prescribe an appropriate orthotic device with the aim to preserve their function and main or improve their ability to walk and perform activities of daily living.

Aims: To investigate what kind of orthotic devices for the lower limb that are prescribed to persons with post-polio syndrome, to what extent these devices are used and to explore the persons' satisfaction with their use of the prescribed devices in daily activities.

Methods and material: Data were obtained from the medical records of a total of 133 persons that had attended a specialised post-polio clinic and from 98 of these 113 persons that responded to a self-report questionnaire. This questionnaire focussed on the use of orthotic devices, the prescription process and aspects of impairments, activity limitations and participation restrictions and their reductions as a result of the prescribed orthotic device.

Results: A majority of the prescribed orthotic devices were insoles and shoes. The participants reported that they used their devices most of the time and that it had a positive effect on their impairments, activity limitations and participation restrictions. They reported that their pain and fatigue was reduced in various daily activities and that their balance and safety during walking had improved. They also reported that the effect of the orthotic device was very much as they expected and that interaction between themselves, the orthotist and the physiotherapist was important.

Conclusions: Orthotic devices prescribed as part of the rehabilitation for persons with PPS is often rather basic but they are used to a great extent and are perceived as beneficial by the persons themselves.

Summary 80**A GUIDELINE FOR THE ORTHOTIC MANAGEMENT IN PATIENTS WITH SEVERE WEAKNESS OR PARALYSIS OF THE LOWER EXTREMITIES****M.A. Brehm, PhD, Senior investigator***Department of Rehabilitation, University of Amsterdam, Academic Medical Center, The Netherlands**E-mail: M.a.brehm@amc.uva.nl*

Introduction: Lower limb orthoses are often applied to improve standing and walking in patients with various medical conditions affecting the neuromuscular and musculoskeletal system. Prescribing such orthoses, however, is a complex process, due to the large variety in musculoskeletal abnormalities, such as the extent and distribution of muscle weakness, possible secondary deformities, and the wide range of available devices. Furthermore, there is a scarcity of guidelines on how abnormalities in the musculoskeletal system should be corrected or supported. This often results in poor clinical decision-making, and thus in suboptimal orthoses.

Aims: To develop and implement a guideline for the orthotic management of lower extremity muscle weakness, in order to support clinical decision-making and improve patient care.

Methods and material: The guideline focuses on conditions with severe weakness of the lower extremities, such as poliomyelitis, Duchenne muscular dystrophy, and spinal muscular atrophy.

Based on the 'Process description for medical devices', all steps in the prescription process are described and protocolized. This was done using the results of scientific research (evidence-based), and consensus meetings of 14 experts in orthotic management, including clinicians, orthotists, researchers, insurance representatives and patients.

Results: Based on consensus, the guideline was put together into a handbook. Currently, this handbook is implemented in three clinical settings, where 15 patients are treated according to the guideline. Supported by the mandating organizations, societies and companies, this will be followed by a grade-by-grade implementation rollout, and by publication of the book. Results will be available in 2012.

Conclusions: This guideline project resulted in a handbook on orthotic management, including theoretical backgrounds, practical instructions, registration forms, and decisions schemes.

Summary 81**ENERGY COST OF WALKING IN PRIOR-POLIO PATIENTS**

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Introduction: Prior-polio patients (PPPs) report weakness, fatigue and decreased mobility. Energy cost of walking (ECOW) is higher than normal and further investigation of relationships between ECOW and other variables was required.

Aims: To measure ECOW using a clinically accessible measure, comparing prior-polio patients to controls and investigate the relationship with other clinical variables.

Methods and material: Thirty PPPs and 30 age/sex-matched controls (HC) were assessed. Variables including ECOW measured using the physiological cost index (PCI), lower limb maximum voluntary isometric contraction (MVIC), Quality of Life using the SF-36, fatigue using the Piper Fatigue Scale (PFS) and pain were recorded. Data was analysed using Microsoft Excel, SPSS and Datadesk packages.

Results: Mean PCI in PPPs was 0.64 ± 0.24 beats/m and 0.30 ± 0.07 beats/m in HC ($p < 0.0001$, 95% CI = (0.23, 0.43)). Regression analysis demonstrated that pain inversely predicted ECOW (Coefficient = -0.64 , $p = 0.004$) and that ECOW inversely predicted the physical component score of the SF-36 (Coefficient = -5.34 , $p = 0.008$). There was a positive correlation between lower limb strength and ECOW ($r = -0.634$). There was no relationship between PFS and ECOW (Coefficient = -2.01 , $p = 0.16$).

Conclusions: ECOW was higher in PPPs than HCs. Lower ECOW is associated with stronger lower limbs, better physical QOL but with more pain. This may be a result of stronger more active PPPs reporting more activity-related pain. Measurement of ECOW provides important information regarding physical functioning of PPPs.

Summary 82**EXERCISE THERAPY AND COGNITIVE BEHAVIOURAL THERAPY IN POST-POLIOMYELITIS SYNDROME: THE FACTS-2-PPS STUDY**

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Introduction: Post-poliomyelitis Syndrome (PPS) is a complex of late onset neuromuscular symptoms with new muscle weakness and increased muscle fatigability as key symptoms. Persons with PPS often complain of severe fatigue and deterioration in functional abilities. Since PPS is not curable, rehabilitation management is the mainstay of treatment. To preserve functioning, two different therapeutic interventions may be prescribed: (1) exercise therapy aiming to improve physical capacity or (2) cognitive behavioural therapy (CBT) aiming to change behaviour, illness cognitions and coping. However, evidence to support either approach is still insufficient. Also, understanding of the mechanisms underlying these approaches is incomplete. Therefore, the FACTS-2-PPS study was designed.

Aims: The primary aim is to study the efficacy of exercise therapy and CBT for reducing fatigue and improving activities and health related quality of life (HRQoL) in persons with PPS. A secondary aim is to identify generic and disease-specific determinants of the obtained effects.

Methods and material: A multi-centre, single-blinded, randomized controlled trial will be conducted. We aim to recruit 81 persons with PPS from 3 different university hospitals and their affiliate rehabilitation centres. Persons will be randomized to one of three groups i.e. (1) exercise therapy + usual care, (2) CBT + usual care, (3) usual care. At baseline, immediately post-intervention and at 3- and 6-months follow-up, fatigue, activities and HRQoL will be assessed.

Results: Currently, 42 patients are included in the study. However, results are not available yet. We hypothesize that exercise therapy and CBT are both effective in reducing fatigue, improving activities and HRQoL of persons with PPS, compared to usual care.

Conclusions: This study will generate new evidence for the rehabilitation treatment of patients with PPS.

Summary 83**VOIDING PROBLEMS IN A DANISH POPULATION OF POLIO SURVIVORS****Lise Kay, MD; Merete Bertelsen PT***PTU – Danish Society of Polio and Accident Victims, Denmark. E-mail: lka@ptu.dk*

Introduction: During the acute polio attack 20% of polio patients experienced voiding symptoms (1). Theoretically of these problems may return with the decline of function experienced by these patients in the long run. Furthermore, other factors such as physical disability to handle toilet visits, and habits brought about by hospital upbringing may also contribute to the problems.

Aim: The aim of the study was to describe whether polio survivors experience more voiding problems than the general population.

Methods and material: An age and sex stratified random sample of 453 polio survivors (age 40-89 years) was drawn among members of PTU (Danish Society of Polio and Accident Victims). A questionnaire concerning voiding was mailed to the selected members. Non responders received a reminder after one month. The questionnaire used was the DAN-PSS (2) which is a validated questionnaire concerning the following voiding symptoms: hesitancy, weak stream, incomplete emptying, straining, frequency, nocturia, urgency, urge incontinence, dysuria, dribbling, stress incontinence and other incontinence.

Symptom prevalence was compared to results from a similar study carried out in a random sample of the general population in a Danish municipality (3).

Results: The response rate was 65 %. Symptom prevalence varied from 13%(dysuria) to 78%(urgency). Approximately twice as many polio survivors experienced voiding symptoms comparing to the normal population. Among polio men the difference was significant for all symptoms except for frequency and dysuria. Among polio women the difference was significant for hesitancy, weak stream, incomplete emptying, frequency, nocturia, urge incontinence and other incontinence.

Among the polio survivors, men significantly more often reported hesitancy, weak stream, straining, dribbling than women, and women significantly more often reported stress incontinence than men. Overall this is in line with the findings in the normal population.

Depending on the symptom 59-97% of the polio survivors reported to be bothered by their symptom. Most troublesome was incontinence symptoms. Compared to the normal population polio survivors more often reported to be bothered by their symptoms.

Conclusions: Results from this study show that polio survivors experience voiding symptoms very frequent and more often than normal population. They are to a large extent bothered by their voiding symptoms, suggesting that focus on alleviating these symptoms can be beneficial for their quality of life. It was not possible to include more than 53 subjects in the age group 40 to 49, and only 15 of them responded. This may bias our results when comparing to the normal population.

Key points:

- Voiding symptoms occur more often among polio patients.
- Further studies are needed to describe the etiology of the symptoms.

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Summary 84**REPORTED PROBLEMS IN RELATION TO OPERATION AND ANESTHESIA A DANISH POPULATION OF POLIO SURVIVORS****Lise Kay, MD; Merete Bertelsen, PT***PTU, Danish Society of Polio and Accident Victims, Denmark. E-mail: lka@ptu.dk*

Introduction: It is said that polio survivors are more sensitive to anesthetics and that they have an increased risk of having complications.

Aim: The aim of this study is to describe the frequency of postoperative symptoms experienced by polio survivors in relation to anesthesia.

Methods and material: Among members of PTU (Danish Society of Polio and Accident Victims) an age and sex stratified random sample of 400 polio survivors aged 50-89 years was drawn. A questionnaire concerning anesthesia was mailed to the selected members with a letter of introduction. Non responders received a reminder after one month.

The questionnaire included questions about symptoms experienced at the acute polio, if operated: the type of operation and anesthesia, post operative experience with regards to waking up, pain and recovery.

Results: The response rate was 71%. In order to avoid problems in relation to obsolete anesthesia, we excluded responders, who had operations earlier than the last 20 years. The following therefore refers to these 92 responders.

Twenty one percent had experienced problems in relation to an operation. Problems reported were: extraordinary pain 8%, a decline in muscle strength 9%, pressure ulcers 1% and extraordinary long waking-up time 16%.

There was no significant relation between respiratory problems at the acute polio attack and prolonged waking up time, but the numbers were very small.

Excluding problems related directly to the operation, the time to regain usual functional ability, varied from 0 to 52 weeks with a median of 1 week.

Conclusions: Results from this study show that polio patients experience postoperative symptoms to an extent that seems to be beyond what is expected from operative patients in general. Prolonged waking up time and muscle weakness are especially problematic. To prevent these problems polio patients should be carefully monitored pre-, per- and postoperatively and attention should be given to the doses of medicine administered.

This study is based on patient experience. A recent study of patient records from Brazil (1) has shown that polio patients can be safely anesthetized as long as their polio symptoms are addressed and they are rigorously monitored.

Key points:

- Polio patients report long waking-up time and muscle weakness after operations, and require careful monitoring of the operative course.
- Data collection from anesthesia reports of a polio population is needed to describe the problems more specific.

Reference:

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Summary 85

VENTILATORY THRESHOLD IN POST-POLIOMYELITIS SYNDROME PATIENTS

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Introduction: Ventilatory threshold is considered one of the best metabolic markers for establishing training intensity to increase aerobic exercise capacity. Patients with post-poliomyelitis syndrome (PPS) often have markedly reduced muscle mass of the lower limbs. It is not known whether in these patients the ventilatory threshold can be determined using submaximal exercise testing.

Aims: To investigate whether the ventilatory threshold can be determined in subjects with PPS using submaximal incremental exercise testing and if not, whether this is related to muscle strength of the quadriceps.

Methods and material: 25 subjects with post-polio syndrome, mean age 58 (SD 9), performed a submaximal incremental exercise test on a cycle ergometer up to 80% heart rate reserve, with continuous recording of gas exchange variables. Ventilatory threshold (VT) was determined using the V-slope method. Peak torque of the quadriceps was assessed during isokinetic contractions at 60°/sec.

Results: VT could be identified in 18 (72%) of the 25 subjects and occurred at a mean heart rate of 120 (SD 15) beats/min (heart rate reserve of 53%, SD 13) and an oxygen uptake of 17.8 (SD 4.5) ml/kg/min. Subjects in whom VT was identified differed from subjects without VT only with respect to maximum power output reached in the incremental test, although mean isokinetic strength values of the both quadriceps were higher in patients with VT (strongest quadriceps: 95 vs. 74 Nm, $p=0.43$ and weakest quadriceps: 43 vs. 19 Nm, $p=0.28$, independent t -test).

Conclusions: In the majority of the PPS patients VT can be determined and lies within the normal range. The absence of VT in some PPS patients is associated with a lower exercise capacity and may be related to a reduced muscle strength. In PPS patients training intensity should be based upon VT.

Summary 86

RESULTS OF 5-YEARS OF LAMOTRIGINE TREATMENT IN PATIENTS WITH POST-POLIO SYNDROME

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Introduction: We previously showed in an open-label study that, lamotrigine at a daily dose of 50 to 100 mg has a positive effect on activity limitations, fatigue and pain after four weeks of treatment, without generating adverse effects.

Aims: To present the 5-years results of lamotrigine treatment in the patients with post-polio syndrome.

Methods and material: We retrospectively evaluated the effects of lamotrigine treatment on the symptoms and life qualities of 30 patients with PPS, who had completed 5 years of lamotrigine treatment without interruption, at a daily dose of 50 to 100 mg.

Results: The severity of pain, fatigue and muscle cramps were rated on a visual analogue scale. Health-related quality of life was measured using the Nottingham Health Profile. The patient's perceived level of fatigue was assessed using Fatigue Severity Scale. Comparing to the baseline values, statistically significant improvements were obtained in the mean scores of VAS, NHP and FSS at the two years and five years in the patients on lamotrigine. Lamotrigine at a dose of 100 mg daily was well tolerated and no undesired major or minor side effects were reported.

Conclusions: Lamotrigine safely relieves the symptoms and improves the life qualities of the patients with post-polio syndrome. Placebo-controlled studies with larger sample sizes are needed to prove the efficacy of lamotrigine.

Summary 87**FRACTURES IN AN AGING POPULATION POLIOMYELITIS SURVIVORS- EXPERIENCE OF THE POST-POLIO CLINIC IN ISRAEL****Shapira Alex, MD***Post Polio Clinic, "Assaf Harofeh " Medical Center, Tzrifin, Israel. E-mail: sander62@hotmail.com*

Introduction: There are many reports on the complications of residual poliomyelitis in the literature, but little attention has been paid to the frequency of one of its serious complication, fractures of long bones. It is, therefore, surprising to find that there are only few reports in the English literature in this century which deals specifically with this problem.

Methods and material: From April 1, 1991 to December 31, 2009, a total of 1807 patients with confirmed diagnosis of paralytic poliomyelitis were evaluated in the post-polio clinic.

Results: During that period 65 fractures occurred among the polio survivors that had been evaluated in our clinic. Most of the fractures occurred while the patients were out patients in our clinic (39).

Most of the fractures were near the knee joint due to falling – distal femur, patella, proximal tibia.

Most of the time the treatment was the same as in the regular population – as cast or operations. Sometimes we found that there is a need to a different way of treatment or different operational instrument – as an example – fracture of the patella .

We have not found more complications of those fracture than regularly except in 5 patients. In those cases the fracture was the trigger to the of post-polio syndrome.

Key points:

- Evaluation of injured poliomyelitis at the emergency room with fractures is necessary to register all the muscles in the limbs to evaluation and treatment. The polio survivor should encourage visiting our clinic periodically at least for muscles evaluation and recording.
- The treatment is not always the same as the normal population and doctors should be aware of it.
- Most of the fractures in the lower limbs of poliomyelitis survivors who treated in the hospital or at our clinic – were around the knee – 39 patients. This was because most cases due to falling when not using long support device as required. Use a long support for walking after fracture does not imply the patient's condition, but to the general degradation of the poliomyelitis and the fracture affirms the need to return to long device.
- Most of the fractions are Low energy and can be treated in the conservative way. No problem recovery of the fracture but its need bring back the poliomyelitis injured patient to every day function as soon as possible.

Summary 88**AN EXPLORATION OF FATIGUE FROM THE PERSPECTIVE OF PEOPLE WITH POST-POLIO SYNDROME****Samantha M. Wong, Assistant Psychologist***The Walton Centre for Neurology and Neurosurgery, Liverpool, UK. E-mail: sammie88@gmail.com*

Introduction: Fatigue is one of the most frequent and debilitating symptoms in post-polio syndrome (PPS). Patients with PPS have reported experiencing separate types of fatigue e.g. physical and mental fatigue.

Aims: To investigate and evaluate the meaning of post-polio fatigue and its associated factors from the patient's own narrative.

Methods: Conversational style, semi-structured interviews were conducted with volunteers with PPS, either face to face or over the telephone. Participants were recruited at a hospital clinic or via the British Polio Fellowship. A topic guide that covered fatigue, general PPS and quality of life issues was used to ensure that information was obtained on all aspects of the participant's experience of PPS. Interview recordings were transcribed and thematically analyzed.

Results: 45 interviews were conducted (23 women and 22 men). No new themes on fatigue emerged during the final interviews, suggesting saturation was achieved. Four types of fatigue were identified, with some patients experiencing one type, and others experiencing all four:- 1) Physical fatigue was generally described as an increasing muscle weakness and loss of strength in previously polio-affected and non-polio affected limbs upon any physical exertion. 2) Mental fatigue was generally described as involving problems with concentration, memory, lack of motivation and/or a feeling of a clouded mind. 3) Systemic fatigue was described as a tiredness throughout the whole body and mind which feels different from ordinary tiredness, 4) Extreme fatigue characterized by a sudden and unpredictable onset of intense fatigue. Physical fatigue was the most prevalent in this sample, followed by mental fatigue.

Conclusions: This study provides a deeper understanding of post-polio fatigue, from the perspective of those with PPS. This is a crucial first step for the development and implementation of more effective fatigue management.

Summary 89

AN EXPLORATION OF THE IMPACT OF POST-POLIO SYNDROME ON NEEDS BASED QUALITY OF LIFE

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Introduction: The needs-based model of quality of life (QoL) proposes that life gains its quality from the capacity of individuals to satisfy their needs (Hunt & McKenna, 1992). Although research suggests that QoL is negatively impacted upon by post-polio syndrome (PPS), no prior research exists to investigate the effect of PPS on needs-based QoL.

Aims: This study aims to be the first to evaluate needs-based QoL in persons with PPS.

Methods and material: Semi-structured interviews were conducted with volunteers who met diagnostic criteria for PPS according to Halstead and Rossi (1985). Participants were recruited from a clinic in Liverpool, UK and through the British Polio Fellowship. Interviews were conversational in style and interviewers sensitively probed how the symptoms of PPS related to the participant's ability to fulfill their day-to-day needs. Interviews continued until saturation was confirmed and were then thematically analyzed.

Results: 45 patients (22 male) took part. Four themes were prevalent in the data. The first of these being the impact of the condition on self-identity and emotional wellbeing. A second theme was fear for the future, e.g. around uncertainty about the progression of the condition. Thirdly, the disease also had a marked effect on the maintenance of relationships with others and fourthly on participation by those with PPS, which adversely affected their social lives and hobbies. Many felt restricted by the limitations imposed by their condition.

Conclusions: Through engaging with the transcript narratives, the negative impact of PPS on needs-based QoL was evident and four clear thematic domains were identified which affected needs-based QoL. Future research could concentrate on developing and validating a measure to evaluate needs-based QoL, specifically in those with PPS.

Summary 90

A POSITIVE TURNING POINT IN LIFE. EXPERIENCES OF A COMPREHENSIVE INTER-DISCIPLINARY REHABILITATION PROGRAMME IN PERSONS WITH POST-POLIO SYNDROME

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Introduction: There is an overall understanding that persons with post-polio syndrome (PPS) can benefit from being admitted to a team specialised in PPS and go through an individualized rehabilitation programme. However, there are very few studies that have evaluated or explored the effects of such programmes.

Aims: To describe and enhance our understanding of how persons with PPS experience the influence of an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme.

Methods and material: Twelve persons (40 to 73 years of age) with clinically verified PPS who had taken part in an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme were interviewed 9 to 18 months after discharge from the programme. The qualitative research interviews were analyzed with the constant comparative method of Grounded theory.

Results: The rehabilitation programme was experienced as a turning-point in the participant's life. Before rehabilitation they felt being in a downward slope without control. Rehabilitation was the start of a process of change whereby they acquired new skills which, over time, contributed to a different but good life. After about a year, they had a sense of control and had accepted life with late effects of polio. They had also established new habits, taken on a changed valued self and could look at their future with confidence.

Conclusions: This qualitative study has shown that persons with PPS can benefit from an individualized, goal-oriented, comprehensive interdisciplinary rehabilitation programme and experience positive changes in their management of daily activities and in their view of their PPS, their future and their self. Furthermore, the results indicate that the effects of an interdisciplinary rehabilitation programme goes beyond that of simply affecting the underlying pathology and reducing impairments.

Summary 91**SELF-PERCEIVED IMPAIRMENTS IN PERSONS WITH POST-POLIO SYNDROME**

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Introduction: Studies of post-polio syndrome (PPS) have assessed whether or not the persons experience a particular impairment, but not to what degree they experience them. Therefore, we do not fully understand the association between various impairments and the person's sex and age, and factors related to the history of their acute poliomyelitis infection and the onset of PPS.

Aims: To assess the degree of perceived impairments in persons with PPS and to determine the association with sex, age, age at and the reported severity of the acute poliomyelitis infection, and the duration of perceived stable functioning and any new impairment.

Methods and material: One hundred and ninety-three persons with prior polio and clinically verified PPS responded to a 13-item self-report questionnaire assessing the physical and psychological impairments as a result of PPS. They rated on a five-point Likert scale (from not at all to extremely) how much, over the past two weeks, they had been bothered by: muscle weakness, muscle fatigue, muscle and/or joint pain during physical activity and at rest, sensory loss, breathing difficulties at rest and during physical activity, cold intolerance, general fatigue, sleep disturbances, concentration difficulties, memory difficulties and mood swings (irritability, anxiety and feeling depressed).

Results: Muscle fatigue, muscle weakness, general fatigue, muscle and/or joint pain during physical activity and cold intolerance were most bothering. Women generally perceived a higher degree whereas older persons a lower degree of some impairments. The degree of perceived impairments was significantly associated with the severity of the acute infection, and the duration of perceived stable functioning and any new impairment.

Conclusions: New impairments are common in persons with PPS but vary depending on sex, age, the severity of the acute infection and factors related to the onset of the new impairments.

Summary 92**SELF-PERCEIVED PARTICIPATION RESTRICTIONS IN PERSONS WITH POST-POLIO SYNDROME BEFORE AND AFTER INTERDISCIPLINARY REHABILITATION**

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Introduction: Rehabilitation programs for persons with post-polio syndrome (PPS) need to focus on areas of participation that are perceived as a problem and promote access to a supportive environment to enhance the participants' participation.

Aims: To assess self-perceived participation restrictions before, after and at follow-up following a comprehensive interdisciplinary rehabilitation programme for persons with PPS.

Methods and material: Sixty-six persons (mean age 64 years) with prior polio and clinically verified PPS participated in an outpatient interdisciplinary rehabilitation programme (average length 6 months). The focus of the programme was to reduce self-perceived disability by providing a variety of interventions and thereby maximize each individual's physical, mental and social potential. All individuals answered the Reintegration into Normal Living Index (RNL Index) at admission, after the programme and at follow-up (on average 6 months after rehabilitation). The RNL Index is an 11-item instrument that assesses self-perceived participation and autonomy, with a focus on reintegration into society.

Results: The average score of the RNL Index indicated that the 66 persons were moderately disabled. There were no significant differences after the programme and at follow-up compared with at admission for the whole group. However, there was a significant correlation between the scores of RNL Index at admission and the improvements ($r = -0.54$; $p < 0.001$) and the number of interventions needed ($r = -0.29$; $p < 0.05$), respectively, and a significant correlation ($r = -0.25$; $p < 0.05$) between the number of interventions needed and the improvement in RNL Index following the programme.

Conclusions: Persons with PPS can experience improved participation and autonomy following a comprehensive interdisciplinary rehabilitation programme. The results also indicate that those with a more pronounced disability at admission and the need for many rehabilitation interventions experience the greatest improvements and therefore seem to benefit most from a rehabilitation programme with regard to self-perceived participation restrictions.

Summary 93

OCCUPATIONS THAT PERSONS WITH POST-POLIO SYNDROME PERCEIVE DIFFICULT TO PERFORM IN THEIR DAILY LIFE

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Introduction: Persons with post-polio syndrome (PPS) can experience a variety of symptoms that can affect their ability to perform various daily occupations. Our knowledge of which occupations persons with PPS perceive difficult to perform is, however, very limited.

Aims: To describe which self-care, productivity and leisure occupations that persons with PPS perceive difficult to perform on admission to rehabilitation; to describe the persons' own perception of the importance, performance and satisfaction with these occupations, and to investigate whether the reported occupations are related to sex, age, working situation, housing and living arrangements.

Methods and material: Sixty-two persons (mean age 61 years) with clinically verified PPS were assessed with the Canadian Occupational Performance Measure (COPM) on admission to rehabilitation. COPM is an instrument designed to capture a client's self-perception of occupational performance. The client identifies occupations in which difficulties are experienced, and the performance and satisfaction with the most important occupations are scored.

Results: A total number of 431 occupations that were difficult to perform were reported, mostly in the COPM occupational area self-care (43%), productivity (32%) and leisure (25%). Household management (27%) and functional mobility (23%) represented half of all the reported occupations. Women reported more occupations related to productivity than men. Persons cohabiting reported more occupations related to leisure than persons living alone. Persons living in a house reported more occupations related to leisure than persons living in an apartment. No differences between the occupational areas were found regarding age.

Conclusions: Persons with PPS perceive a wide range of occupations that are difficult to perform. This indicates that a client-centered approach and instruments that capture the complexity of daily occupations are needed in order to plan appropriate rehabilitation interventions for persons with PPS.

Summary 94

A BRIEF HISTORY OF POST-POLIO IN THE UNITED STATES

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Aims: To describe the history of the late effects of polio in this country from the early 1980s to the present.

Methods and material: Using the keywords post-polio, post-polio syndrome, late effects of polio, post-polio sequelae and post-poliomyelitis, we reviewed the number of articles in English listed in PubMed at 5 year intervals between 1980–2009. In addition, we compiled data from Post-Polio Health International records on the number of post-polio support groups and polio-dedicated clinics at 5 year intervals from 1985–2010.

Results: In 1980 there was one article dealing with post-polio issues. This number increased dramatically during the 1980s and early '90s peaking in 1995 when 64 were published. This number declined over the next 14 years to a low of 18 in 2009. Support groups and clinics showed a similar pattern of rise and decline with a maximum of 298 support groups in 1995 and of 96 clinics in 2000. These numbers declined to 131 and 32, respectively, by 2010. These data reflect a well-defined history of post-polio in this country that spanned approximately 30 years. During the 1980s and early 90s, there was a period of optimism that energized research, clinical and self-help initiatives. As the limits of these efforts became apparent during the late 90s and early 2000s, resources and activities declined resulting in frustration and disillusionment within the post-polio community.

Conclusions: The late effects of polio were an unexpected sequelae of the mid-century polio epidemics in this country that resulted in a rise and fall of polio-related activities confined to a span of 3 decades. Nevertheless, there are still many thousands of polio survivors who will continue to need physiatric services for many years to come.

Summary 95**POST-POLIO SYNDROME IN BRITISH COLUMBIA, CANADA****Joan Toone, President PPASS BC***Post Polio Awareness and Support Society of British Columbia, Canada (PPASS BC)**E-mail: jtoone@ppassbc.com*

PPASS BC is a non-profit registered society of approximately 500 members. British Columbia is the third largest province in Canada and the most westerly. We have divided our province of 365,000 square miles into twenty-nine Area Groups. Each group is led by an Area Group Contact who is the liaison between members and our office on Vancouver Island which means we can quickly provide information to all members. Our bookkeeper/office manager works 8 hours a week, everyone else is a volunteer. We have a Board of Directors that meet via teleconference monthly so anyone in the province may take part.

PPASS BC brings awareness about PPS to communities through accurate information and presentations. We provide a source for current knowledge, research and treatments available for those with post-polio.

Each issue of our newsletter contains a medical insert and is distributed bi-monthly and traded world-wide. We have translated some of our articles to enable more people to have access to our information. We work with physiatrists, doctors and rehabilitation centres as well as the BC Centres for Disease Control, Health Canada, BC Community Healthcare and BC Immunization. As the survivors of polio we have a unique view of the value and need for immunization which we are eager to provide.

We have three Water Exercise Programs. PPASS BC has produced a recipe book and a Water Program Manual. We have printed two Memory Books of members' personal stories. These Memory books have allowed some members to tell their story for the first time and we are now gathering stories for a third edition. We have provided several pieces of medical equipment for hospital facilities.

We speak to a variety of groups such as Rotary and Nursing or Health Care Students and provide a power point presentation of relevant pictures explaining the history of polio and resulting Post-polio Syndrome. We speak one on one with nursing students about polio and coping with post-polio.

We wish to communicate with groups worldwide to seek a better understanding of other PPS groups and their approaches to post-polio. We are willing and pleased to share any of our information with others.

Summary 96**POLIO SERVICES VICTORIA: AN AUSTRALIAN APPROACH TO EFFECTIVE CARE FOR POLIO SURVIVORS THROUGH A "HUB AND SATELLITE" MODEL****Doran Blaise, BSc (Hons), PT***Polio Services Victoria, St Vincent's Hospital, Victoria, Australia. E-mail: Blaise.Doran@svhm.org.au*

Aim: To demonstrate the feasibility of care delivery over large distances with a small team of health professionals, using metropolitan (hub) and regional (satellite) clinics and providing state-wide advice and education to service users and healthcare professionals.

Summary: Polio Services Victoria (PSV) was founded in 1998 and is based at St Vincent's Hospital in Melbourne, Australia. It provides state-wide care to polio survivors, with around 1300 individuals known to the service. The majority live within the catchment of metropolitan Melbourne but around one fifth lives in regional Victoria and some travel from interstate. The service has four health care professionals: the orthotist and physiotherapist (who is also coordinator) are full time; the occupational therapist and rehabilitation consultant are part time.

Clinics involve a comprehensive initial assessment by the rehabilitation consultant, physiotherapist and orthotist, with follow up reviews generally occurring at three, six or twelve month intervals. As the land area of Victoria is approximately five times that of Denmark, it is neither feasible nor reasonable for all clients to come to metropolitan clinics. To overcome this, PSV organizes 6 regional clinics across the state each year. The venues alternate biennially between 12 regional centres. For polio survivors, this model of care is unique in Australia. The mandate of the service is to provide:

- Specialist assessment and collaboration with external health service providers to develop individualized client care plans.
- Good quality information to other health service providers, clients who have had polio and to the wider community.
- Within the mandate the service aims to maximize the independence and participation of individuals under our care through:
- Providing specialist support for the client and external service provider throughout the episode of care.
- Facilitating access to appropriate services and resources for the individual and their significant others.
- Liaising closely with voluntary and support organizations across the state of Victoria.

Future directions for the service will include improving access and information to new migrants, asylum seekers and refugees - a population that is approaching 20% of our new referrals. This group will present different challenges as, whilst they are mostly younger than our current service users, they are from culturally and linguistically diverse backgrounds and few have received formal therapy for their polio-related impairments. We will also be investigating the effectiveness of holding solely allied health clinics in regional centres, as many of the problems that present in those clinics do not need the intervention of a rehabilitation consultant.

Summary 97**A SOCIOLOGICAL STUDY: FAILURE OF POLIO ERADICATION PROGRAMME IN INDIA**

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Introduction: India has the largest percentage of Polio affected children in the world. However, the response against the further spread of Polio Viruses in the country is being hindered by stigma and discrimination. In order to develop effective intervention programmes to control and reduce the further spread of the disease, it is first important to understand the nature of Polio-related stigma and especially how people construct it. In the Proposed study, the social construction of Polio-related stigma among Muslims was investigated because high levels of stigma were found in this group. This was fuelled partly by the belief that Polio was not a serious problem amongst Muslims. In the other hand in my four year research as a participant observation, I found that it is very difficult to eradicate polio from India. Problems are seen not only community level but surveillance level too. The proposed research investigates that Major problems are within surveillance of WHO, 99% Indian male Doctors in surveillance of WHO are neither social nor fare towards minority community. Surveillance Medical Officers (SMO) always misguides higher authorities of WHO. Higher authorities of WHO in India always listen to Doctors and considers their Views never listen the views of other workers especially field volunteers who are back bone of the projects.

Aims: The main aim of the study is to examine the perception of Doctors and Polio-related stigma among Muslims and Doctors. The study will also explore the causes of failure of WHO-NPSP project in India.

Methods and material: Method used for the study is Exploratory in nature. Data is directly taken from the field-Delhi, Uttarpradesh and Bihar. The transcript analyzed using thematic content analysis to determine the themes that emerged from the research material.

Results: The main findings of the study includes Negative attitudes of Doctors towards Muslims, Field Monitors and social causes of failure of NPSP – WHO Projects.

Conclusions: Field Monitors working for the Polio-eradication are backbones of the programme. They are less paid, Long Working Hours (18 Hours), High burden of work, badly behaved by Surveillance Medical Officers of WHO, Ground level facts are veiled, higher authorities misguided by Surveillance Medical Officers.

Summary 98**POST-POLIO SYNDROME: SITUATION IN SPAIN AND PROPOSALS FOR ACTION**

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Introduction: The 1950's polio epidemic in Spain had a lower incidence than in Northern Europe. This may explain why, even nowadays, the Post-Polio Syndrome (PPS) is not a standardised condition in the framework of social and healthcare assistance, but is generically included in the context of poliomyelitic sequelae, even in public documents of the Spanish Society of Neurology.

Ordered by Parliament, the Ministry of Health requested a report from our Agency concerning the situation of PPS in Spain: nature, epidemiology, and proposals for healthcare and social services for affected individuals.

Aims:

- Estimate PPS prevalence in Spain.
- Propose standardised criteria to define differential PPS diagnosis;
- Propose the basis for programmes for:
 - information for patients and professionals;
 - follow up of subjects at risk;
 - management of affected subjects including healthcare attention and social services.

Methods and material:

- Systematic literature review.
- Review national polio case notification registries (1940 to 1970) and comparison with data from other countries.
- Review national database of individuals with disabilities.

Results: Incidence rates per 100,000 inhabitants varied between 0.6 (1964), after massive establishment of vaccination, and 7.12 (1959), when vaccination still remained discretionary.

Today, there could be 36,500 individuals affected by PPS according to the number of people with diagnosis of poliomyelitic sequelae which are registered in the National Database of Disability.

The variability in describing the disability degree due to PPS by medical professionals creates a lack of equity.

Conclusions: The following proposals were made to the Ministry of Health:

- Standardise diagnostic criteria and assessment techniques, possibly on the basis of "March of Dimes".
- Inform GP's so they can forward cases to specialised services.
- Broaden orthoprosthetic benefits, including certain materials that, at this moment, are restricted to other serious disabilities.
- Elaborate a national registry of polio survivors to aid in providing information and follow-up.
- Standardise reclassification criteria regarding degree of disability, for social and labour purposes.

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AUTHOR INDEX

- A**
 Abma, Tineke A. 44
 Accler, Michele 16
 Akthar, Ehtesham 62
 Amate, Jose M. 62
 Appelin, Katja 60
 Atwal, Anita 27
 Avlund, Kirsten 35
- B**
 Baj, Andreina 14
 Barnes, Michael P. 15
 Beelen, Anita 12, 15, 23, 24, 28, 29, 35, 36, 39, 56
 Bertelsen, Merete 55
 Bertolasi, Laura 16, 33
 Bickerstaffe, Alice 24, 36
 Blaise, Doran 61
 Bocker, Barbara 40
 Bono, Giorgio 14
 Borg, Kristian 13, 14, 15
 Boserup, Esther 13
 Bouza, Carmen 62
 Bradai, N. 25, 35
 Brehm, Merel A. 12, 29, 36, 39, 53
 Broberg, Susse 34
 Brogårdh, Christina 48, 49
 Bundgaard, Peter 10
- C**
 Castellote, Juan M. 62
- D**
 Dall'Ora, Elisa 16
 Danzi, Bruno 16
 Diaz-Horta, Oscar 14
- E**
 Espelund, Christina 53
- F**
 Farbu, Elisabeth 15
 Ferlisi, Monica 16
 Ferris, Ramesh 19
 Flansbjerg, Ulla-Britt 48
- G**
 Gilhus, Nils Erik 15
 Glaser, Judith 52
- H**
 Halstead, Lauro S. 60
 Harlaar, Jaap 36
 Harrison Calmes, Selma 20, 31
 Hartvigsen, Anna-Lene 37
 Headley, Joan L. 11
 Henley, Cynthia 51
 Hölig, C. 40
 Hou, Linda 52
 Howard, Robin 15
- K**
 Kallehauge, Holger 45
 Kay, Lise 23, 32, 55
 Koopman, Fieke S. 12, 15, 54
- L**
 Laffont, I. 25, 35
 Laub, Michael 21, 31
 Laure-Kamionowska, Milena 50
 Lexell, Jan 9, 25, 35, 43, 48, 58, 59
 Liethof, Mary-Ann 18
- M**
 Maccari, Giuseppe 14
 Martini, Millo 16
 Martin, Rebecca 10
 Matyja, Ewa 50
- McFarlane, John Richard 45
 Millia, Jamia 62
 Monaco, Salvatore 16
 Murray, Deirdre 24, 54
- N**
 Nielsen, Claus Vinther 43
 Nollet, Frans 10, 12, 15, 17, 23, 24, 28, 29, 35, 36, 39, 40, 44
 Noppe, Kees 36, 40
- O**
 Ocanhas, Mirca 41
 On, Arzu Yagiz 16, 48, 56
 Öncü, Jülide 19, 38, 50
 Opara, Josef 15
 Östlund, Gunilla 22, 29, 32
- P**
 Pimazzoni, Fabiana 16
 Pomeroy, Ian 49
 Prytz, Svend 21, 31
- Q**
 Quadros, Abrahao Augusto Juviniano 41
 Quincey, Anne-Marie C. 26, 58
- R**
 Rogers, Barbara 34
 Ruetz, Axel 51
- S**
 Salomonsson, Sylvi 44
 Santos Tavares, Iolanda 42
 Saz-Parkinson, Zuleika 62
 Schanke, Anne-Kristine 27
 Schipper, Karen 44
- Shanahan, Anne 18
 Shapira, Alex 57
 Silva, Tatiana Mesquita e 47
 Skough, Katarina 33
 Smolenski, U.C. 40
 Sportouch, P. 25, 35
 Staehelin Jensen, Troels 29
 Stålberg, Erik 15
 Stenström, Anders 20, 31
 Stibrant Sunnerhagen, Katharina 22, 30
 Stolwijk, Janneke 23, 35
- T**
 Taylor, Charlotte Lucy 47
 Tennant, Alan 26
 Tersteeg, Irene 23, 35, 42
 Thorén-Jönsson, Anna-Lisa 32
 Toniolo, Antonio 12, 14
 Toone, Joan 61
- U**
 Uegaki, Kimi 15
- V**
 Van Den Berg, Maayken 62
 Visser de, Marianne 15, 17
 Voorn, Eric L. 39
 Willén, Carin 38
 Wollam, Kathryn 51
 Wong, Samantha M. 26, 57
- Y**
 Yelnik, Alain 25, 35
 Young, Carolyn 26
- Z**
 Zanusso, Gianluigi 16

