POST-POLIO HEALTH INTERNATIONAL 10th International Conference

Living with Polio in the 21st Century

April 23-25, 2009

Saturday, April 25, 2009

Session S1, 9:30–10:45 am
through
Session S4, 2:45–4:00 pm

This book belongs to

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Post-Polio Health International
Including International Ventilator Users Network

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QUESTIONS from the audience will be submitted to the speaker/moderator in writing unless otherwise announced in the session.

Post-Polio Health International (PHI) thanks the presenters for providing the excellent information contained in the daily program books.

If you share this information, we respectfully ask that you acknowledge the presenter and that the information was disseminated at PHI's 10th International Conference: Living with Polio in the 21st Century (April 2009). PHI will incorporate additional information presented at the conference and make it available to attendees and others at a later date. Details will be published in *Post-Polio Health* and on www.post-polio.org.

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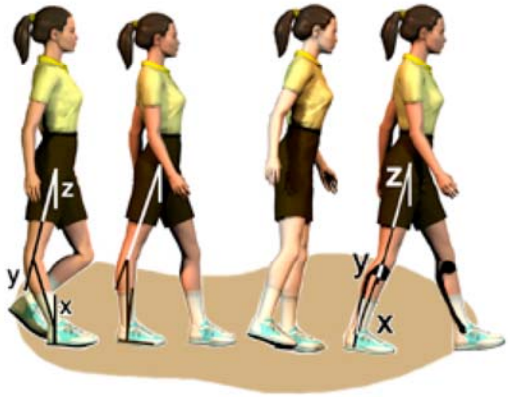
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Welcome to the Roosevelt Warm Springs Institute for Rehabilitation.

Whether you have been here before or this is your very first time on our campus, we are thrilled to have you here as our guests. As you may know, we are the “living legacy” of FDR’s vision for healing, so as you enjoy your symposium you will notice patients and students coming and going, and that we are very much a living and breathing rehabilitation center. We have been providing rehabilitation for 81 years, and you will also note that parts of our campus show our age.

We are not a modern conference center like you may find in downtown Atlanta, but we have something that they don’t. My hope for you during your visit is that you experience what we call the “Spirit of Warm Springs,” which refers to our caring and compassion. We are very proud of our historic legacy, and I encourage you to reflect on that as you travel around and across our campus. Franklin D. Roosevelt never learned to walk by coming here, but I believe it made him a better man and a much better President. So on behalf of all of us who come to work here every day in pursuit of the same mission “to empower individuals with disabilities to achieve personal independence” as FDR did, welcome to this place of healing. May you enjoy your conference and fully enjoy your stay with us.

Greg Schmieg
Executive Director, RWSIR

From Post-Polio Health International (PHI):

Welcome to the tenth in our series of international conferences.

PHI's goal for these conferences has always been threefold: First, we aim to promote the face-to-face exchange of authoritative, up-to-date information about the late effects of polio and independent living with its consequences. Second, we aim to sustain a productive network of active polio survivors and healthcare professionals with relevant expertise – by providing a forum in which these two groups can inform each other and interact. Third, we aim to disseminate the results of our conferences to all those interested polio survivors and medical professionals who are unable to attend.

We are honored to have this conference at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR). RWSIR's place in the history of physical medicine and rehabilitation is a prominent one indeed. It began with Franklin Delano Roosevelt, and with the idea of rehabilitation as a cooperative venture between medical professionals and polio survivors. From its beginnings, like PHI, it has also been dedicated to helping people develop and sustain the functional abilities necessary for independent living with a physical disability.

This event was made possible by the dedicated labors of many staff members at RWSIR. To all of them, we owe our thanks. We also thank Carolyn Raville, founder of the North Central Florida Post-Polio Support Group, for suggesting a post-polio conference at RWSIR.

Thank you for joining us to learn about "Living with Polio in the 21st Century."

Lawrence C. Becker
Chair, Board of Directors, Post-Polio Health International

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Program / Saturday, April 25, 2009

8:30 am – 9:30 pm
Registration in GEORGIA HALL

8:30 am – 9:30 pm
Continental Breakfast

9:30–10:45 am
SESSION S1 OPTIONS

First Step in Pain Treatment: Finding the Cause

ROOSEVELT HALL AUDITORIUM

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Paul Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Dale C. Strasser, MD, Emory University School of Medicine, Atlanta, Georgia

Research Progress

VRU AUDITORIUM

Summary of Post-Polio Research at Montreal Neurological Institute & Hospital

Daria A. Trojan, MD, Montreal Neurological Institute & Hospital, McGill University, Montreal, Quebec, Canada

Summary of Post-Polio Research at Karolinska Institutet (1/2 hr)

Prof. Kristian Borg, MD, PhD, Stockholm, Sweden

Bladder Inconveniences

MEADOWS CLASSROOM

Lise Kay, MD, *Urologist,* PTU – Landsforeningen af Polio-, Trafik- og Ulykkesskadede, Rodøvre, Denmark

The Secret to Good Attendant Care

SCHOOLHOUSE 105

Gene Spalding, BSEE, ATP, Warm Springs, Georgia

Report from the Camp Dreamers: Review of the Wellness Retreat

SCHOOLHOUSE 111

Frederick Maynard, MD, UP Rehabilitation Medical Associates, Marquette, Michigan

Sunny Roller, MA, Mary E. Switzer Distinguished Research Fellow National Institute on Disability and Rehabilitation Research, Ann Arbor, Michigan

11:15 am – 12:30 pm
SESSION S2 OPTIONS

Second Step in Pain Treatment: Choosing Therapies

ROOSEVELT HALL AUDITORIUM

William DeMayo, MD, John P. Murtha Neuroscience and Pain Institute (JPMNPI), Johnstown, Pennsylvania

Dale C. Strasser, MD, Emory University School of Medicine, Atlanta, Georgia

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Paul Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia

Learning from Wise Elders

SCHOOLHOUSE 111

Sunny Roller, MA, Mary E. Switzer Distinguished Research Fellow National Institute on Disability and Rehabilitation Research, Ann Arbor, Michigan

Poly Pharmacy: Making It All Work

VRU AUDITORIUM

Kathy Wilson, RPH, RWSIR, Warm Springs, Georgia

Too Hot and Too Cold: Causes and Solutions

SCHOOLHOUSE 105

Carol Vandenakker, MD, University of California Davis Health System, Davis, California

When Are Trachs an Option?

MEADOWS CLASSROOM

Linda Bieniek, CEAP, LaGrange, Illinois

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Kristy McClellan, RT, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

11:30 am – 1:30 pm

Lunch on Your Own at the RWSIR Cafeteria. Vegetarian available. (Attendees will choose from Session S2 or S3 and eat lunch during the other time slot.)

1:00 – 2:15 pm

SESSION S3 OPTIONS

Post-Polio Research: Progress, Possibilities and Problems

ROOSEVELT HALL AUDITORIUM

Prof. Kristian Borg, MD, PhD, Karolinska Institutet, Stockholm, Sweden

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

Daria A. Trojan, MD, Montreal Neurological Institute & Hospital, McGill University, Montreal, Quebec, Canada

Rahnuma Wahid, PhD, Manager Analytical Immunology, Sanofi Pasteur, Swiftwater, Pennsylvania

Bracing: What's New? Is Old Better?

VRU AUDITORIUM

Moderator: Marny Eulberg, MD, St. Anthony's Family Medical Center West, Denver, Colorado

Curt Kowalczyk, CO, Otto Bock HealthCare, Minneapolis, Minnesota

Marmaduke Loke, CPO, Dynamic Bracing Solutions, Inc., San Diego, California

Mark Taylor, MLS, CPO, FAAOP, University of Michigan, Ann Arbor, Michigan

Exercise and Activity: How Much and What? Let's Get Practical

SCHOOLHOUSE 111

Merete Bertelsen, PT, The Danish Society of Polio and Accident Victims, Rodøvre, Denmark

John G. Fan, MD, Hutchinson Clinic, Hutchinson, Kansas

Demystifying the Equipment of Assisted Breathing

MEADOWS CLASSROOM

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Kristy McClellan, RT, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Betsy Thomason, BA, RRT, Millennium Respiratory Services, Whippany, New Jersey

2:45 – 4:00 pm

SESSION S4 – CLOSING PLENARY

Polio: A Look Back at the Public Health Crusade that Mobilized a Nation

ROOSEVELT HALL AUDITORIUM

David M. Oshinsky, Jack S. Blanton Chair in History, and Distinguished Scholar in Residence, New York University

5:30 pm

DINNER AND ENTERTAINMENT AT CAMP DREAM

SESSION S1

First Step in Pain Treatment: Finding the Cause

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida
Paul Peach, MD, Palmyra Post-Polio Clinic, Albany, Georgia
William DeMayo, MD, John P. Murtha
Neuroscience and Pain Institute (JPMNPI),
Johnstown, Pennsylvania
Dale C. Strasser, MD, Emory University School of Medicine, Atlanta, Georgia

The First Step in Treating Pain: Finding the Source

Amy Clunn, MD, Southeastern Rehabilitation Medicine, Ocala, Florida

Dr. Clunn will present the common pain generators in polio patients and help identify ways that the patient can better communicate with his or her physician in regard to symptoms, and outline the process by which the physician should identify the pain generators so that effective treatment can be determined.

Dr. Clunn completed medical school at the University of Cincinnati in 1993, followed by internship at Oakwood hospital and an additional 3 year residency in physical medicine & rehabilitation at the University of Michigan in Ann Arbor, where she also served as chief resident. She now practices with Southeastern Integrated Medical. Pl., a multidisciplinary integrated health system in North Central Florida, (in Ocala) full-time.

Dr. Clunn is board certified in Physical Medicine & Rehabilitation and also in the subspecialty of Pain Medicine. She is a member of the American Academy of Physical Medicine & Rehabilitation, The American Academy of Pain Medicine & the American Academy of Electrodiagnostic Medicine as well as the Florida Medical Association, Florida Society of PM&R and the Marion County Medical Society. Dr. Clunn is the Physician consultant for the North Central Florida Post-Polio Support Group.

Polio survivors have been found to have multiple potential sources of pain as they age. The pain can interfere with function and add further physical decline, lead to depression, poor sleep and fatigue, which are already problems in most post-polio patients. Therefore it is important to be aggressive in treating pain in order to optimize physical and mental function.

The primary findings on physical exam in polio patients are muscle weakness and atrophy (shrinkage) in the affected limbs. Part of the post-polio syndrome includes progressive weakness with or without atrophy in the limbs that were affected originally, and occasionally in limbs that were not affected originally. The atrophy and weakness occurs because the virus affected the anterior horn cell of the peripheral nervous system in a patchy pattern. This then causes the nerve supply to be poor to the receiving muscle, and it can no longer work fully (the nerve supply is the hard wire that gives the muscle its power and its signal to move). Without actively contracting, the muscle atrophies (shrinks) rapidly. What is left is a muscular system that must struggle to maintain posture, activate joints and work with possibly only 10-80% of its usual power. With this understanding of the disease mechanism , it is easy to see the first reason polio patients often have pain: chronic muscle strain. The muscles in the affected limbs are often overused or strained even in everyday activities such as walking or using arms. Muscle strain pain presents with aching soreness and soreness in muscles that become tender to touch. The tenderness can be in the belly of the muscle or at its distal, tendinous insertion near the bone (enthesopathy).

Bones and joints are another source of pain in polio. If a bone is not subjected to regular weight-bearing activity, it becomes osteoporotic (loses its mineral content). This can cause pain and lead to compression or stress fractures that can occur even with normal activity (walking or bending for example). Stress or compression fractures present with acute, focal intense pain, often with swelling, made worse with weight-bearing. It is even more important that post-polio patients undergo bone density studies than the normal population in order to treat osteoporosis if it exists, as it predisposes bones to fractures with falls or even atraumatic activities. Joints can become painful due to arthritis or due to contracture from tightness. Capsulitis (inflammation of the joint capsule) can also occur and presents with very painful and restricted range of motion of a joint. This is particularly common when weakness has made it difficult to move a joint, and the capsule shrinks or tightens because it is not ranged. Subluxation (slippage of a joint out of position) can be commonly found in feet, sacroiliac (pelvic) joints and shoulders when the surrounding musculature is weak. This presents as pain in range of motion or with weight-bearing, deformity, or crepitation with range of motion.

Nerve pain can present as part of an "overuse " syndrome when certain activities are overdone, often in response to substituting one function for another where weakness exists. An entrapment of the nerve can occur with the repetitive motion. An example of this is carpal tunnel syndrome, particularly common in manual wheelchair or walker users (repetitive gripping with or without direct compression), or a gluteal nerve injury in response to hip weakness and pelvic instability and strain with walking.

Spine pain is also common in polio patients. Spine pain has potential sources such as discs, joints, muscles, ligaments, tendon, bone and nerve roots. Wheelchair users are susceptible to degenerative disc disease (seated position increases intradiscal pressure), atrophy of the paraspinal muscles and scoliosis (curvature). Sitting also creates tightness in tendons of flexor muscles and can lead to pain when in extension, such as lying down. Joints in spines where weakness is present in a lower limb or in the spine itself are subject to premature and more severe arthritic change than usual. Discs are also subject to more strain injuries such as tears and herniations when gait is unbalanced. They present with intense focal back pain and, if pressure on the nerve root ensues, radiating pain to the abdomen, groin or leg & foot (if lumbar). Osteoporosis also affects the spine commonly with compression fractures.

The circulatory system can also be affected by polio, particularly in limbs that are paretic (weak or paralyzed), and in wheelchair users due to sitting. Venous return of the blood is usually impaired in this instance, and blood can pool in the extremity causing swelling, aching and even ulcerations. Patients can get angina (chest pain due to cardiac ischemia (decreased blood flow) due to cardiac disease hastened by lack of cardiovascular exercise.

If polio survivors are facing any pains that are severe or that last more than a few weeks, they should have an evaluation by a musculoskeletal physician, primarily orthopedists and physiatrists. A careful history should be taken, including information regarding the patient's polio history, other past medical history, functional history and how the pain problem is affecting mobility. The patient should be clear and give an example, such as, "I used to be able to lift a gallon of milk with my right arm and now it is difficult to hold a coffee cup." This tells the examiner the time frame of the problem as well as the severity. After that, a thorough physical examination should follow including gait evaluation, if the patient is able. Strength, range of motion, sensory testing and inspection/palpation of the affected areas should be evaluated. Subsequent diagnostic testing may be necessary, including x rays, MRIs, bone scans, EMGs and lab work. With this information an appropriate diagnosis can be rendered with treatment to follow.

Beware: One of the worst things a polio survivor can do is feel that all his or her symptoms are part of a post-polio syndrome and think that nothing can be done to help. Hopefully this talk has given polio patients the knowledge to understand some of their unique potential pain generators and what can be done to evaluate them (and formulate a treatment plan).

Pain Symptoms in Polio Survivors

Paul E. Peach, MD
Medical Director, Palmyra Post Polio Clinic

Pain Symptoms are common in many polio survivors. Pain may be related to underlying post-polio syndrome, while in many cases, may also be due to unrelated causes. Therefore, an important first step is in accurately diagnosing the etiology (or, in some cases, etiologies) of the pain. Once the diagnosis is made, appropriate interventions can be undertaken. Common pain symptoms that are polio related include pain due to muscle pain, joint pain, tendonitis and pain due to compressive neuropathies. Most are due to underlying overuse patterns and with appropriate strategies for alleviating these stressors, significant pain reduction often follows.

Research Progress

Summary of Recent Post-Polio Research at the Montreal Neurological Institute and Hospital

Daria A. Trojan, MD, MSc
Physiatrist
Montreal Neurological Institute and Hospital
McGill University
Montreal, Quebec, Canada

We have completed and published several clinical research studies of relevance to post-polio patients over the last few years. Our studies have focused on pathophysiology, on fatigue, and on osteoporosis.

The cause of post-polio syndrome (PPS) is still unclear. Several hypotheses have been proposed including distal degeneration of enlarged post-polio motor units which develop during recovery from paralytic polio, motor neuron loss, normal aging, overuse, disuse, and immunological mechanisms. Gonzalez and co-workers (2002) reported increased mRNA levels of pro-inflammatory cytokines (signaling molecules) in the cerebrospinal fluid (and not the blood) of 13 PPS patients compared to normal controls. We have extended these findings by measuring the actual levels of several pro-inflammatory markers in the blood of 51 PPS patients and comparing them to 26 healthy controls. Another aim of the study was to evaluate the association of elevated inflammatory markers with several clinical parameters including muscle strength, fatigue, and pain. We found that the levels of several inflammatory markers (TNF-α, IL-6, and leptin) were increased in the blood of PPS patients compared to normal controls. Increased levels of TNF-α were associated with pain, specifically muscle pain. The reason for the increased inflammatory markers is unknown, but our findings indicate that inflammation may play a role in the ongoing PPS disease process.

We have also been interested in the area of fatigue in PPS and post-polio patients. Fatigue occurs in most PPS patients and is usually reported as the most disabling symptom. Two studies have been completed. The first was concerned with sleep disordered breathing in fatigued post-polio clinic patients and the second with biopsychosocial correlates of fatigue.

Sleep disordered breathing is the general term used to describe different types of breathing disorders during sleep. Three types of breathing disorders during sleep have been described: obstructive, central, and mixed apnea and hypopnea. Obstructive sleep apnea and hypopnea is characterized by repeated episodes of upper airway collapse during sleep, despite attempts at breathing. This can cause reduced blood oxygen levels during sleep and fragmented, poor sleep. These difficulties can lead to daytime fatigue and somnolence (sleepiness), as well as a number of neurocognitive difficulties (such as problems with attention and concentration) and medical difficulties. In the general population daytime sleepiness and fatigue can improve dramatically with treatment such as nasal continuous positive airway pressure (CPAP). Central apnea is characterized by cessation of airflow without attempt at breathing. Mixed apnea is a combination of the two. The aim of our study was to determine the frequency, predictive factors, and symptoms predictive of sleep disordered breathing in fatigued post-polio clinic patients. The study was a cross-sectional study involving a chart review of 590 post-polio clinic charts. 98 patients were included and all had a complete overnight polysomnogram (sleep study) in a sleep laboratory, 98% in the same laboratory. The gold standard for the diagnosis of sleep disordered breathing is in-laboratory, technician-attended, complete overnight polysomnography. An apnea-hypopnea index (AHI) was calculated. AHI is the total number of sleep related events per hour of sleep, and is used to assess the severity of sleep disordered breathing. The frequency of sleep disordered breathing was 65% (AHI≥5) and 50% (AHI≥10). The most common type was obstructive sleep hypopnea, present in 86% of patients with sleep disordered breathing. Most patients had mild (43%, AHI 5 to 15) or moderate (42%, AHI 15 to 30) sleep disordered breathing. A smaller proportion had severe sleep disordered breathing (16%, AHI > 30). Age, sex, age at acute polio, time since acute polio, weakness and respiratory difficulties at acute polio, speech and swallowing difficulties at acute polio and at evaluation, body mass index, pulmonary function measures, alcohol use, sedative drug use, smoking, fibromyalgia, kyphoscoliosis and scoliosis and ear/nose/throat surgery were not predictive of sleep disordered breathing. Snoring was more common in subjects with sleep disordered breathing. We conclude that sleep disordered breathing is very common in fatigued post-polio clinic patients referred for sleep evaluation. Obstructive hypopnea was the most common type. Snoring was the only clinical symptom that tended to predict sleep disordered breathing. Based on our results, we recommend that all post-polio patients with daytime fatigue and somnolence atypical for PPS undergo evaluation for sleep disordered breathing.

Our second study of relevance to fatigue was concerned with the development of biopsychosocial models for fatigue in PPS. Our aim was to determine the biopsychosocial correlates of general, physical, and mental fatigue in PPS, by measuring the additional contribution of potentially modifiable factors after accounting for important non-modifiable disease-related factors. 52 ambulatory PPS patients were included. Fatigue was assessed with the Multidimensional Fatigue Inventory (MFI) which assesses fatigue on five subscales (General Fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation, and Mental Fatigue) and the Fatigue Severity Scale (FSS) which assesses fatigue in medical and neurological disease. We were concerned with general, physical, and mental fatigue because all three types of fatigue are reported in patients with PPS. Potential correlates for fatigue that we considered were disease-related factors (acute polio weakness, time since acute polio, PPS duration, muscle strength, pain, forced vital capacity, maximum inspiratory pressure, maximum expiratory pressure, body mass index, disability, fibromyalgia), behavioral factors (physical activity, sleep quality), and psychosocial factors (depression, stress, self-efficacy). Multivariate regression models were calculated for MFI General, Physical, and Mental Fatigue and for the FSS. Age-adjusted multivariate models with non-modifiable factors were first calculated. Then, age-adjusted models were calculated by determining the additional contribution of potentially modifiable variables while keeping the previously identified non-modifiable variables in the models. We found a different pattern of variables to be associated with general, physical, and mental fatigue. In multivariate models, correlates of general fatigue included disease-related and psychosocial factors. Correlates of physical fatigue were disease-related and behavioral factors. A correlate of mental fatigue was a psychosocial factor. A portion of fatigue could be explained by potentially modifiable factors. Because we identified several potentially modifiable predictors for both general and physical fatigue, our results suggest that an interdisciplinary rehabilitation team management program that can address several contributors to fatigue would likely be most useful in managing these fatigue types.

We have also been interested in the area of osteoporosis in post-polio clinic patients. Osteoporosis is a progressive skeletal disorder characterized by low bone mineral density that results in bone fragility and an increased tendency to fractures. Weakness is a risk factor for osteoporosis. Osteopenia is a decrease in bone mineral density and can be a precursor of osteoporosis. The aim of our study was to identify the frequency of osteoporosis at the hip and lumbar spine in a post-polio clinic population and to evaluate the association of muscle strength in the legs and other possible contributors contributing factors to osteoporosis with bone density results at the hip. The study was cross-sectional involving a chart review. 379 charts were reviewed and 164 patients were included. Most bone densitometries were performed at the same center with assessments at the hip and lumbar spine. Muscle strength was evaluated by manual muscle testing during a clinic neurological examination. The frequency of osteoporosis at the hip and lumbar spine was 32% and 10% of men, 9% and 6% of pre-menopausal women, and 27% and 11% of post-menopausal women. In a logistic regression multivariate model, the presence of osteoporosis at the hip was significantly associated with strength sumscore in the same leg in which the bone density was performed after adjusting for other important risk factors (age, body mass index, time since polio). We conclude that osteoporosis occurs commonly at the hip in post-polio clinic patients and that hip bone density is related to reduced muscle strength in the same leg. Based on our results, we recommend that all post-polio patients be evaluated for osteoporosis at both hips (or less preferably at the hip of the weaker leg) and at the lumbar spine.

Our studies had several limitations that were discussed in detail in the original publications. All studies summarized above were cross-sectional. Because of this, the temporal relationships and causal effects of the associations observed are unknown. In addition, our study of biopsychosocial models for fatigue in PPS had a relatively small sample size for this statistical technique. A larger sample size could have allowed us to find other contributors to fatigue in multivariate models.

In conclusion, we recommend that all post-polio clinic patients be evaluated for osteoporosis, and that all post-polio patients with fatigue or somnolence atypical for PPS be evaluated for SDB. Both disorders occur commonly in a post-polio clinic population. An interdisciplinary team approach may be best for management of several contributors to general and physical fatigue, but further randomized, controlled studies are necessary. Our finding of raised blood inflammatory markers in PPS, together with results from other research teams, prompt further prospective evaluation of the role of inflammatory mediators in the etiology and symptomatology of PPS.

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Post Polio Research at Karolinska Institutet

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From the beginning of the 1980:s our research group has performed clinical, pathophysiological and interventional studies in the field of post-polio. The group has produced three dissertations and has three planned dissertations in the coming years. The research was in the first phase concentrated on neurophysiological and muscle morphological studies with a focus on consequences of compensatory mechanisms in overused muscles. During the last decade the research has been focused on immunology and intervention with immune modulation with intravenous immunoglobulin (IVIG) and on finding a biomarker in patients with post-polio syndrome (PPS). Furthermore, we have studied different aspects of quality of life in patients with fatigue and pain.

Overuse of muscle and compensatory mechanisms

Data from earlier studies from our group support the hypothesis that PPMD is due to denervation. Neurophysiological studies have shown signs of ongoing denervation which also is supported by findings of atrophic muscle fibres in muscle biopsies (Borg et al 1988, Borg and Henriksson 1991, Borg and Edström 1993). Macro-EMG studies have shown that the motor units in PPS patients are 5-10 times larger than normal indicating reinnervation by means of collateral sprouting (Tollbäck et al 1993). In other studies the largest motor units have been shown to decrease over time suggesting a failing reinnervation in PPS patients. Thus, the new or increasing muscle weakness in post-polio patients may be due to a denervation-reinnervation process that have reached its upper limit, i.e. the insufficiently compensated denervation leads to muscle weakness (Borg 1996).

Reinnervation is probably the most powerful compensatory mechanism. However, there are other compensatory and adaptive mechanisms in muscles of PPS patients leading to an increase of the contractile tissue or changing the contractile properties. Muscle fibre hypertrophy and an increased frequency of type I muscle fibres have been reported in the anterior tibial muscle (Borg et al 1988, Borg et al 1989) and Tollbäck (1995) found that the overused motor units had lost their differentiation and were activated in an all-or-none fashion. The motor unit properties were changed towards a uniform type with intermediate properties favouring strength before endurance and driven into contractile fatigue more easily than normal units (Tollbäck 1995).

In a double-blinded placebo controlled study study muscle training with substitution of enzyme Q-10 was evaluated. The exercise resulted in an increase of muscle power but there was no difference between Q-10 and placebo (Skough et al 2008). A rehabilitation programme based mostly on physiotherapy has been evaluated and found to increase quality of life mostly for mental but also for physical domains (Jung et al 2008a).

Immunological aspects of PPS and outcome of immunmodulatory treatment

Several authors have suggested that an immune response could be one explanation for PPS. In some studies an ongoing inflammatory process in the spinal cord of PPS-patients and oligoclonal bands in CSF have been detected. When evaluating cytokines in cerebrospinal fluid (CSF) of PPS patients we found an increase of cytokines, Il-4, TNFa and IFNg, (Gonzalez et al 2002). The levels were in the same range as those found in Multiple Sclerosis (MS), a well-known neuroinflammatory disorder. In a pilot study a down-regulation of the cytokine levels was seen after intravenous treatment with immunglobulins (IVIG), (Gonzalez et al 2004). This was followed by an increase of muscle strength as well as quality of life, especially for vitality (Kaponides et al 2006). This was confirmed in a randomized, multi-centre and placebo-controlled study (Gonzalez et al 2006) in which an increase of muscle strength as well as quality of life for vitality and general health was found. Decrease of the cytokine levels and the clinical effect lasted for one year (Gonzalez et al 2009a). After 2.5 years the cytokine levels were back to the levels seen before IVIG treatment and the clinical effect had vanished (Gonzalez et al 2009b). In an open clinical study Werhagen et al (2009) found that around 2/3 of 64 PPS patients had a decrease of pain after IVIG treatment.

In order to analyze the occurrence of systemic inflammatory changes muscle biopsies were studied applying more modern immuncytochemical techniques. We were able to find minor signs of inflammation in some of the PPS patients (Melin et al 2009). An increase of serum lipids have been reported in PPS patients. One might speculate that this is due to a systemic inflammatory process. However, we were not able to find a decrease of serum lipids after IVIG treatment (Melin et al, personal communication) and we are now comparing data from PPS patients with normal data in order to evaluate if there is a serum lipid increase in PPS patients.

Biomarkers for PPS

In a recent published study (Gonzalez et al 2009c) proteomics were performed on CSF from PPS patients. A highly predictive and disease-specific differential expression was found in five proteins. The findings provide argument for an ongoing nervous tissue damage in PPS and the proteins are also involved in apoptosis. Further studies are performed in order to correlate these findings to clinical parameters in order to evaluate the clinical significance of the different proteins as biomarkers for PPS. The possibility of a connection with spinal muscular atrophy was disclosed by a normal SMN gene finding (Bartholdi et al 2000). However, other potential genetical factors should be explored.

Pain, fatigue and quality of life in PPS

During the acute polio infection, the patients had signs of meningitis and there has been a discussion of whether or not the increased tiredness and mental fatigue may be due to an affection of higher CNS functions. In a few studies around half of the PPS patients had signs of affection of cognitive functions. We have not been able to reproduce this finding in a Swedish PPS population (Östlund et al 2005).

In contrary to the common belief, PPSpatients perceive less pain and vitality increases with increasing age (Östlund et al 2008). Furthermore, an increase of quality of life with increasing age and with male gender was found when performing SF-36 questionnaire in a large PPS cohort (Jung et al 2009a). It was also found that vitality in PPS patients was mostly of a physiological character in PPS patients and that mental fatigue was not a prominent feature(Östlund et al 2008). We have also been able to identify a subpopulation of PPS patients that were extremely fatigued (Östlund et al 2009). This group of patients were younger than the rest of the PPS patients and a thorough psychological analysis is now being performed. Analysis of pain in PPS patients showed that approximately 10% of the patients had neuropathic pain (Werhagen et al 2008). When neuropathic pain was present there was always a concomitant disorder for example lumbar disc hernia. Neuropathic pain was in most cases relieved by operation or medication.

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Bladder Inconveniences

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Why should polio survivors experience bladder inconveniences?

In order to see how the scene could be set for polio survivors to be at risk of having bladder inconveniencies we have to return to the acute phase of polio – is there evidence it affected the bladder and voiding process? From the epidemics of acute polio voiding disturbances are reported with a prevalence of around 20% (1-4), the prevalence being higher among adults than among children. The problem was by far urinary retention but incontinence also occurred as did serious urinary stasis and urinary stones. Symptoms usually lasted for a week, but permanent damage occurred in 15% of the cases.

Living with polio, however, also increase the risk of having bladder dysfunction. In order to understand that we will have to have a look at bladder anatomy, bladder function, nerve supply and factors affecting the voiding process.

Normal bladder function and voiding process

The bladder is a balloon situated in the pelvis. The detrusor muscle is situated in the bladder wall and by contraction it is able to create pressure and empty the bladder for urine. A successful voiding requires, however, that the sphincter relaxes at the same time. The sphincter is part of the pelvic floor and supported by it. The bladder has two functions: storage of urine controlled by the sympathetic nervous system and voiding controlled by the parasympathetic nervous system. In the baby these two functions automatically follow each other: the bladder fills, when it is full it empties. The first years of life the central nervous system matures and makes it possible for the individual to be conscious of the bladder and to control the voiding process. However, voiding is influenced by several additional factors other than intact nerves and muscles: Urine production, bladder capacity, opportunity, disease, upbringing, culture, habits, and psychological factors contribute as follows:
Urine production: depends on the amount of fluid in the body, consequently on the intake of fluid. The production is in general 1-1.5 litre per 24 hours, and the normal voiding volume 200 cc. Urine production is normally reduced at night under the influence of antidiuretic hormone.

Bladder capacity: normally the first desire to void is felt at about 200 cc, but suppression of voiding can be held to up to half a litre or more. A small capacity gives frequent voiding, and a large capacity – with some exceptions – gives infrequent voiding.

Opportunity: If you do not have nearby toilets with easy access you might come in trouble. Certain occupations as f. ex. bus drivers are at known risk of have problems on this account.

Habits, upbringing, and culture: your decision of when is it appropriate to void is influenced by these factors.

Psychological factors: stress and excitement gives a tendency to void while engagement tends to make you forget to void.

Disease: infection and tumours may give frequent voiding.

How do polio survivors have an increased risk of bladder dysfunction ?

Impaired muscles and nerves: a weak detrusor muscle may result in incomplete voiding, leaving residual urine behind. The bladder is as a consequence soon full again, and voiding becomes frequent. It may become so frequent that incontinence will be the experience. At worst there is no detrusor muscle contraction at all and a total retention of urine develops.

A weak sphincter/pelvic floor results in impaired ability to keep tight and dripping of urine will occur, especially in connection with jumping, laughing and coughing (stress incontinence).

The autonomic (sympathetic and parasympathetic) nervous system, that controls body functions other than striated muscles, may be imbalanced and give rise to difficulties in inhibiting voiding desire (urge-incontinence) (parasympathetic preponderance) or difficulties in initiation of the voiding process (sympathetic preponderance).

Disease: urine is a wonderful media for bacterial growth and sets the scene of frequent infections
Upbringing: in the forties and fifties the attitude in good nursing was to keep things on a fixed schedule, and for voiding this meant that children in hospitals were brought up to suppress their need for voiding until it was scheduled. Bad habits and overstretched detrusor muscle fibres could be the consequences.

Opportunity: weak muscles in arms and legs may make it difficult to get to toilet in time to avoid an accident.

Bladder capacity: weak detrusor muscle, hospital upbringing, bad opportunities and habit result in large bladder capacity, where as sympathetic preponderance may give a small bladder volume.
Urine production: in paralysed legs oedema build up during the day. When the force of gravity is reduced in bed, retained fluid is mobilised and excreted, resulting in a larger urine production at night.

Work-up for bladder dysfunction

Primary work-up: comprises of 3 simple tests and a screening for other diseases. First of all a drinking/voiding chart for three days should be fulfilled by the patient:

Time	**Drinking volume**	**Voiding volume**	**Leakage/activity**
	cc	cc	
	cc	cc	
	cc	cc	
	cc	cc	
	cc	cc	

A measurement of the velocity of the urinary flow is done by having the patient urinate into a flowmeter, and the residual urine (the volume of urine left after voiding) is measured by an ultra sound. Screening for disease is done by urinary stick (blood, infection), vaginal-rectal examination and ultra sound.

This work-up is often enough to get to diagnosis and treatment. If further work-up is needed the patient should be referral to an urologist for a full urodynamic investigation.

Treatment

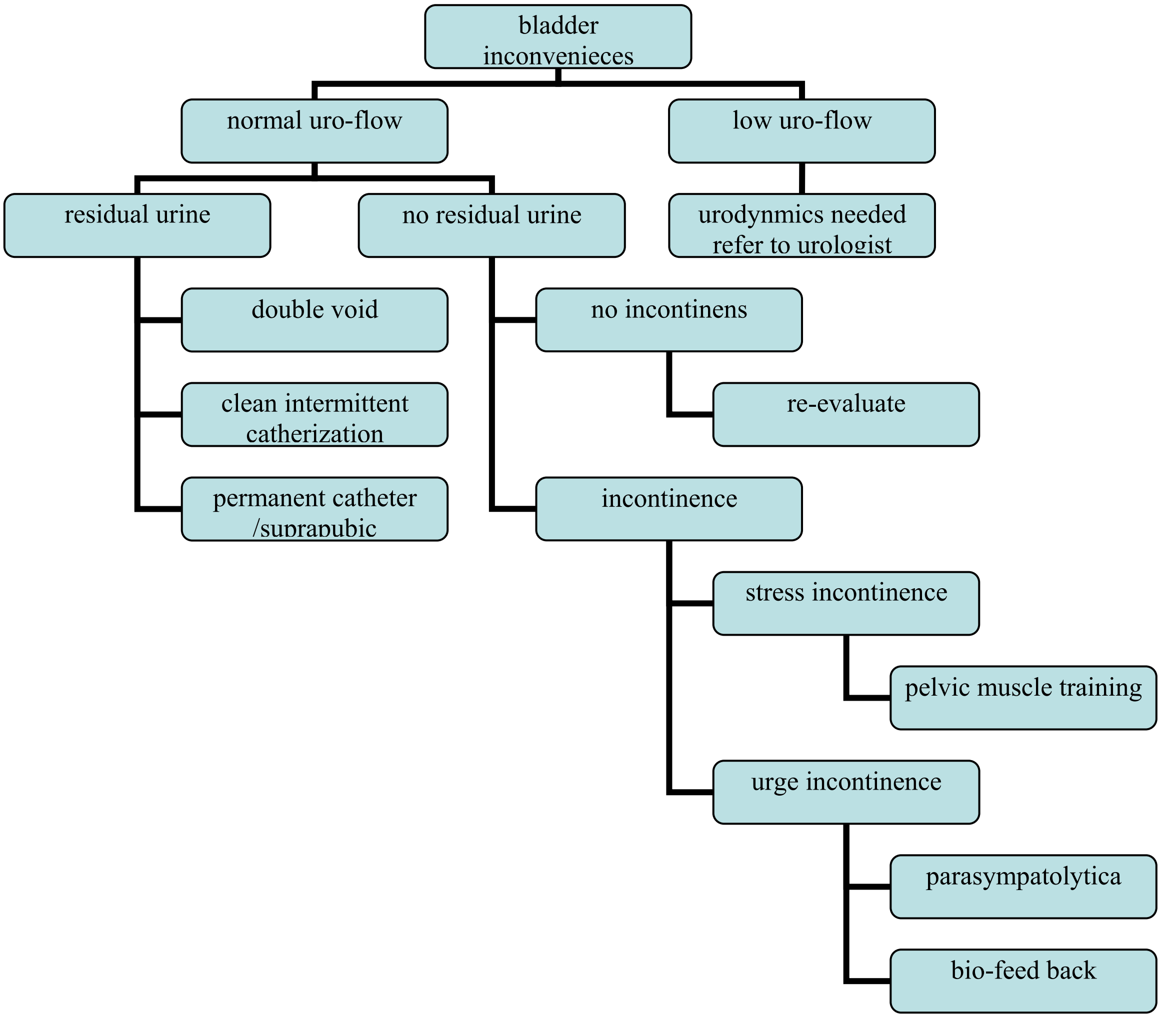
General advice: intake of liquid should be around 2 litres a day, less in the evening or before critical events (as going out). Voiding should also be performed before critical events (as going out or to bed) and with a frequency that gives a voiding volume of 2-300 cc with around 3 hours interval in the day time. Easy access can be important, in order to reach the toilet in time from the first desire to void until voiding is possible. This can implicate adjustments of both house and clothing.

Oedema: If the patient presents with oedema of the legs and the voiding chart shows a large urine production at night, oedema can be prevented in the daytime by elevation of the legs and/or an elastic stocking, and supplemented by a mild diuretic at 5 p.m. when necessary.

Residual urine: first step in the treatment of incomplete emptying (residual urine > 100 cc) is to double void (i.e. void once again at the same visit to the toilet). If this is not sufficient Clean Intermittent Self-catheterisation should be initiated. Most patients are able to do that with the supervision of an experienced urological nurse. The last choice is permanent a catheter, preferably as a suprapubic catheter inserted above the pubic region. This way of insertion gives less discomfort especially in connection with physical activities.

Urinary flow: if the urinary flow is low (< 15 cc/sec) or if it is impossible to obtain volumes > 100 cc the patient should be referred to a full urodynamic investigation.
Incontinence: stress incontinence may be treated by training of the sphincter/pelvic floor, where as urgeincontinence may be treated by bio-feed back and/or parasympatolytica (Darifenacin, Oxybutynin, Solifenacin, Tolterodin).

Summery of work-up and treatment for bladder inconvenience when other disease has been excluded



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The Secret to Good Attendant Care

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Report from the Camp Dreamers: Review of the Wellness Retreat

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The purpose of this presentation is to describe the Post-Polio Wellness Retreat program and provide an evaluation in order to encourage replication of similar retreats in new localities.

The Post-Polio Wellness Retreat at Roosevelt Warm Springs Institute for Rehabilitation (RWSIR) was a five-day residential health promotion program customized for polio survivors. Its design was built upon a model program that was successfully conducted in upper Michigan in 2006, 2007, and 2008. For more information, go to http://www.baycliff.org/ and link to Post Polio for a video review. Overall participant feedback from the Michigan program was positive:

> *"It's the best thing I ever did in my life."*
>
> *"The retreat went far better than I had ever dreamed. Everyone was so positive and it met all of their goals and expectations. The sense of group support, acceptance and camaraderie was remarkable!"*
>
> *"I can tell it will be a lifetime turning point for me."*

Developed and led by Frederick M. Maynard, M.D. and a selected planning committee, the 2009 wellness retreat at RWSIR's wheelchair accessible Camp Dream provided an affordable and unique opportunity for 60 participants to take time away from their daily routines to totally focus on their post-polio health and well-being. Retreat attendees set their own learning and health goals for the week. Based on the premise that attention to good health should include all of a person's interlaced parts---mind, body and spirit--participants attended daily educational sessions. Some were didactic with discussion; most were experiential. These were scheduled as a morning lecture and discussion for the entire group, followed by several choices of smaller group programs throughout the day. Morning activities included a choice of exercise sessions. Then following lunch and a one-hour rest period, the afternoons were devoted to two-hour recreational options and then breakout sessions on a variety of topics. Massages, manicures, facials and haircuts were offered throughout two of the days. After supper, the evening programs included full group singing around a campfire, listening to the firsthand stories of a local "historian" about the area, a movie followed by group discussion, and time to visit and play board games.

With a theme of "Discovery," the basic curriculum more specifically encompassed the following selection of sessions.

- Full Group Instruction with Discussion
    - Post-Polio Wellness: A Holistic Overview Including the Role of Complementary and Alternative Medicine
    - The Post-Polio Body
    - The Mind: Self-Management Strategies for Wellness
    - Inspiration and Wellness: How Spirit Affects Health
    - Bringing It All Together: Reflection and Carry Over

- Morning Exercise
    - Strengthening and Stretching
    - Restorative and Non-Fatiguing Yoga
    - Aquatics
    - Cardiovascular Training
    - Tai Chi
    - Exercise for Shoulder Problems

- Recreational Options
    - Adaptive kayaking
    - Adapted golf, bowling
    - Fishing
    - Adaptive biking and hand cycling
    - Arts for Healing
    - Tour of Historic Sites
    - Warm pool swimming
    - Nature walk and roll
    - Experiencing Massage, a Manicure, a Facial

- Afternoon Breakout Sessions
    - Ask the Doctor: Orthotist and Physical Therapist: Bracing and Walking Aids
    - Ask the Doctor: Pain Management
    - Ask the Doctor: Fatigue Management
    - Ask the Doctor: General Medicine
    - Ask the Dietician: Weight Loss Strategies
    - Healing with Botanicals
    - Ask the Pulmonologist and Respiratory Therapist: Breathing Problems
    - Ask the Physical Therapist: Seating to Alleviate Pain
    - Ask the Nurse: How to Best Access and Use Complementary Medicine
    - Ask the Nurse: Osteoporosis Wellness and Management
    - Ask the Psychologist: Stress Management and Relaxation Techniques for Chronic Pain
    - Caregivers and Spouses: A Time Together
    - Integrating Spirituality
    - The German Health Spa Program: What If You Went to a Spa?
    - Acupuncture
    - Acupressure

This five-day residential wellness retreat, led by post-polio medical specialists and key polio survivors can provide a useful model for post-polio groups internationally and around the U.S. who wish to sponsor similar programs in their areas. Those who would like to initiate plans for a similar retreat may want to consider the following planning steps:

1. Find a Wheelchair Accessible Camp or Overnight Retreat Center
2. Establish a Planning Committee with Core Faculty Including Retreat Co-Directors and an On-Site Program Coordinator
3. Create a Program Budget and Plans for Funding
4. Design a Schedule of Daily Retreat Activities
5. Select and Prepare Additional Session Instructors/Facilitators
6. Publicize the Retreat
7. Select and Prepare Retreat Participants
8. Conduct the Retreat
9. Evaluate the Retreat's Success Level
10. Inform and Help Others Succeed in Conducting a Post-Polio Wellness Retreat

Participant evaluations of the retreat are helpful. The following questions may be asked as part of this process:

For each session they attended,

1. Was the content useful?
2. Which parts in particular?
3. What is one idea or activity you plan to make part of your normal routine within the next few months?
4. Please comment on the facilitator's delivery, pace, ability to relate to the group and ability to individualize material to meet your needs.
5. Overall how would you rate the session:
   5 excellent 4 good 3 average 2 below average 1 poor
6. Did you feel strengthened, refreshed and enlivened at the finish of this session? If yes, why? If no, why not?
7. Overall how would you rate the retreat:

5 excellent 4 good 3 average 2 below average 1 poor

What needs to be changed?

What was especially good?

Faculty and participant comments and evaluations at this Conference presentation of the Camp Dream experience will provide further programming insights and a foundation for the design and delivery of similar post-polio wellness programs.

For more information, contact Retreat Co-Directors, Frederick M. Maynard, M.D. at fmaynard@penmed.com and Sunny Roller, M.A. at elsol@umich.edu

SESSION S2

Second Step in Pain Treatment: Choosing Therapies

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Neuroscience and Pain Institute (JPMNPI),
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Learning from Wise Elders

Sunny Roller, MA, Mary E. Switzer Distinguished Research Fellow National Institute on Disability and Rehabilitation Research, Ann Arbor, Michigan

This presentation reports the results of a two-part 2006 study funded by the National Institute of Disability and Rehabilitation Research entitled, *Adaptation Into Late Life for Persons with Long-Term Neuromuscular Disabilities: Lessons Learned from Polio Survivors.* The purpose of the presentation is/was to report the findings of the study and to discuss, with a panel of four study participants (from Arizona, Maine, Connecticut and Michigan), and the presentation audience applications for living successfully into late life with a chronic disability from polio. A summary of the study results follows.

Primary Study: Late Life Lessons Learned from Polio Survivors

Abstract

Even though people with a prolonged disability from causes such as poliomyelitis, spinal cord injury, spina bifida, and cerebral palsy are quickly emerging as a large elder population with accelerating needs, their patterns of adaptation into late life are ill defined. To describe late life success strategies, this investigation concentrated on the perceptions of a small and elite set of polio survivors--those who were designated the most highly regarded by their peer group as senior role models (or polio mentors), who were over 65 years of age and more than 50 years past disability onset.

The goal of this study was to expand knowledge about the late life physical, social and environmental adaptation experience of older individuals who contracted poliomyelitis between 1930 and 1955. To accomplish this purpose, specific physical changes, attitudes, coping techniques and adaptive behaviors facilitating improved quality of life over the life span and into late life were identified. To achieve the study

objectives, the PI, a polio survivor herself,[1] employed qualitative social research methodology, complemented by quantitative measures to describe the sample and document perceptions.

The four research questions guiding the study addressed the following topics: (a) issues polio mentors faced at various stages of the life course; (b) how perceptions of life with a disability changed over time; (c) attitudes viewed as most valuable for coping well with new issues into late life and how these attitudes differed from past ways of thinking; (d) how polio mentors defined "successful adaptation" in late life.

Objective measures of stress and life satisfaction were used to describe the sample. From a national network of post-polio support groups, purposive sampling was used to select 15 study participants with 93 respectively linked support group members in five regions of the U.S. During the study year, in-depth, audio taped semi-structured interviews (in person or by telephone) were conducted with the 15 key participants, who also completed the objective measures noted above. Qualitative analysis was performed using standard qualitative techniques (constant comparative method). Quantitative analyses included descriptive and inferential statistics.

Key Findings:

- Major issues throughout life included: achieving and maintaining independence which required diligent effort; fighting shame and creating a positive self-image with a disability; and reconciling social and functional losses
- Over time, perception of life with a disability from polio changed for this group. Before encountering the late effects of polio at mid-life, individuals operated and worked hard using their "lens of difference," a self-perception that rejected the shame and prevalent social stigma of disability. High achievement was crucial. Later in life they became more willing to look at their lives through the "lens of disability," more fully embracing their disability as part of their overall personal identity. In so doing, they found a new freedom to be more content with this new self-perception and life in their retirement years.
- Key coping strategies included having a strong social support system, enjoying life, being optimistic, self-acceptance, assertiveness, education and spirituality.
- Successful late life adaptation was defined as self-acceptance and adaptation, having the right resources, and being surrounded by loved ones.

Discussion

Successful late life adaptation was commonly defined as an outgrowth of self-acceptance and adaptation, having the right resources, and being surrounded by loved ones. These guidelines were built upon earlier life lessons that were revised for success in later life.

Over the lifespan, this group's perception of living with a disability from polio had changed. The years with polio during childhood, adolescence and as an adult were not comfortable. Before encountering the late effects of polio at mid-life, individuals operated and worked very hard using their "lens of difference," a self-perception that rejected the shame and powerful social stigma of disability. High achievement was crucial. Later in life, due to changing societal attitudes and new public policy, and out of practical necessity, this group became more willing to look at their lives through the "lens of disability," more fully embracing their disability as part of their overall personal identity. Once retired, there was no longer, for example, a need to prove oneself in the mainstream workplace and keep up with non-disabled competitors. These polio mentors seem to have found a new freedom to make further disability-related adaptations and be more content with who they really were becoming, and what they needed to do to live well during retirement years. Ironically, growing older with greater disability has offered this group a fresh sense of not only comfort, but also liberation. In many important ways, life was reported as better in old age than it ever was in youth.

Pilot Sub-Study: Describing Polio Survivors in Terms of Wisdom

Abstract

Some authorities say that wisdom, rather than intellectual knowledge is crucial for aging well, yet understanding and applying the notion of wisdom in the area of personal growth and successful aging among people with disabilities has not been attempted until now. To complement the larger study, a sub-study to explore characteristics of wisdom in this group and their polio support group peers was conducted. The purpose of this concurrent pilot study was to begin to describe polio survivors in terms of their individual perceptions about wisdom as well as Monika Ardelt's concept of wisdom. Ardelt's notion of wisdom is defined in terms of three separate, but interconnected ways of dealing with life: cognitive (intellectual objectivity), reflective (comprehending differing perspectives) and affective (empathy and compassion). The study's objectives were to document how polio mentors personally describe wisdom and its current role in their lives, and to describe the difference between Ardelt's measured wisdom levels in polio mentors and their support group peers. The total N for this sub-study was 108. A mixed-methods approach was utilized: qualitative inquiry complemented with use of the Three-Dimensional Wisdom Scale (3D-WS), Ardelt's quantitative measure. The primary study's sample of 15 key participants was 1) asked several questions about wisdom and 2) to complete the 3D-WS. After being invited by the groups' leaders, 11 of the 15 key participants' support groups volunteered to complete the 3D-WS, resulting in 93 responses. Qualitative analysis was performed using the constant comparative method. Quantitative data were analyzed using one-sample and independent samples t-tests to compare all elders to all support group members.

Key Findings:

- Participants defined wisdom as a combination of education and knowledge, the ability to see situations from another's point of view, and the ability to actively help, listen and share with others. The role of wisdom in their lives was described as being directly related to actively assisting their post-polio peer group.
- As a group, key participants scored significantly higher than support group members on the wisdom scale in the area of reflective wisdom only.

Discussion

Upon reflection, the basic conclusion of this pilot study might be summed up as one wise elder said, "my own wisdom is from things that I've experienced, places I've been, people I've known. Things I've done. That's absolutely the way I see my wisdom." This group's wisdom is real, but unique. This elite group of 15 polio survivors has lived with a chronic disability for more than 50 years, adapting so well they have become elected as "adaptation role models" by their observing peer group. When reviewing this preliminary information, several patterns about their distinctive form of wisdom have emerged.

Key participants defined wisdom as a combination of education and knowledge, the ability to see situations from another's point of view, and the ability to actively help, listen and share with others. The role of wisdom in their lives was described as being directly related to actively assisting their post-polio peer group, which would, of course, be different than that of a cross section of elders in the non-disabled population. These elders did not necessarily see themselves as wise among all men, but they humbly agreed that they did have some type of wisdom based on their unique life experience with polio. Their support groups, by way of this study, had just verified that distinction for them. They could help and advise others from that perspective. It should be noted that one limitation of this study was that there was no direct question asked to further discover how they actually saw themselves more globally in terms of wisdom. Did they feel that the combination of their polio and overall life experience had offered them a wisdom that matched the wisdom levels of society's other wise people?

It is interesting to examine this group's unique form of wisdom based on the results of Ardelt's quantifiable measure. As a cluster, key participants scored significantly higher than support group members on the wisdom scale in the area of reflective wisdom only. In terms of compassion (affective) or thinking/knowledge (cognitive) levels, the 15 did not score any higher that the rest of the support groups as a whole. This may say that the sample of wise elders was selected because they were perceived by their peer group as understanding and able to view life from the perspectives of others, specifically them. They were the individuals who could step outside of themselves and offer an objective point of view to those who needed them. It may be that their ability and willingness to look at phenomena and events from different perspectives may have actually been a key coping tactic that had to be developed over the years to compete and thrive in a non-disabled society. It has been deduced in various writings that any member of a minority group in a diverse society that is led by a privileged majority must study the ways of the majority in order to interact with them well and succeed. For example, although this is changing, black people in the American culture have said they needed to study and understand white people's ways if they were going to do well in a white-dominated society. So this is also likely to be true for those who are disabled in a non-disabled culture. In order to get what one needs to fit in, to become part of the mainstream, the disabled person must take the initiative to understand the dominant majority. (What is valued and important to that person? What does he want to achieve? What emphasis does he place on his and others' physical strength and prowess? How patient is he? How helpful is he? What does he need?) Perhaps it is only seldom that an able bodied person needs to, or chooses to understand the person who is disabled, at least at first meeting. It may be that at least for these selected polio survivors, the responsibility of understanding the other's perspective was well learned throughout life and then easily applied to support group members now in later life.

It is also worthy of note that as a group on the 3D-WS, being a post-polio wise elder is not positively related to the affective dimension of wisdom. Their lowest scores were in this area. Not only that, but the affective dimension of wisdom was correlated negatively (although not significantly due to the small number of cases) with life satisfaction. Hence this group's strong suit was not necessarily sympathetic and compassionate love for others. It may be that for this group, because of their life experience with disability, survival goals often had to trump compassion. Early on they learned that they had to work through the pain they may have felt physically through the years and rise above it. They had no time to feel sorry for themselves if they wanted to make it in society. They had to "use it or lose it" and press forward with persistence when they did not feel like it. At times this may have even seemed a bit self-abusive. Rehabilitation professionals and parents were tough on kids with polio because they were seen as having much weakness to overcome. Hence this study's subjects warned others about not associating with negative people too much. They would drag them down. Because they had to go beyond their own self-pity to overcome disability, they did not approve of self-pity in others and expressed low tolerance for "whiners." As one participant said, life with polio could make a person "damn tough."

Of this Ardelt comments, "I think avoiding "negative" people might be a good strategy for one's own well-being, but truly wise people are not affected by the negativity of others and, hence, are able to spend time with them and even help them to feel better. They can truly love the enemy." But does this reflect the practical real life wisdom of survivors of disabling diseases such as polio? It would be interesting to investigate whether excellent health lends itself better to extending greater compassion toward others than does disability. It may also be that the wisest of the wise elders are the ones who revealed that their experience with disability is now, in later life, making them more compassionate toward others with a disability, because they have grown in greater self-acceptance with their own disability.

…"having good people around me, especially happy, positive people that love to laugh and—that does a lot for me, to help me…"

Polypharmacy: Making it all Work

Kathy Wilson, RPh, RWSIR Director of Pharmacy,
Warm Springs, Georgia

Polypharmacy can be defined as the use of multiple medications for the treatment of a patient's medical conditions. The term polypharmacy suggests that more medication is being used than is clinically indicated. The number of meds taken by a patient that constitutes polypharmacy has not been defined. There are several reasons for poly pharmacy:

1) As the population ages, polypharmacy increases. The elderly often require multiple medications to treat multiple health-related conditions.
2) Patients with multiple co-morbid medical conditions also require numerous medications to treat each condition. It is not unreasonable for patients with multiple comorbid medical conditions to be on 6 to 9 medications to reduce his or her long term risk for those conditions, i.e, diabetes complications and coronary events.
3) A recent hospitalization also puts you at risk of polypharmacy. Medicines are started and stopped quite frequently during your hospital stay.
4) Multiple doctors are prescribing medications for the same patient. Once a patient starts a medication, it is never discontinued.
5) Doctor changes from one med to another within the same therapeutic class; but the patient doesn't stop taking the first med. For example: You are taking Protonix 40mg and Dr. gives you a prescription for Prevacid 30mg. Both of these drugs are in the same therapeutic class "Proton Pump Inhibitors" and work the same way. No one should be on both these meds. Prescription drugs switching to over-the-counter (OTC) status is another problem area in this therapeutic class. A patient may take Prilosec (OTC) and get a script for Protonix, Prevacid,, etc. This is why it is so important that you take all the meds you take on a regular basis with you when you go to the doctor.
6) Doctors also may have a patient on a brand name drug and write the next prescription for a generic drug. Example: A patient is taking Coumadin 5mg daily; the Doctor gives patient a prescription for Jantoven 5mg, another tradename for Coumadin. The patient continues to take both not realizing they are the same medication. This could have devastating consequences.
7) In an effort to cut costs, patients fill prescriptions at several pharmacies. Once you choose the most cost-effective pharmacy, stick to one pharmacy. One pharmacy would have a complete list of all your meds to better inform you of duplications, interactions, etc.
8) Lack of patient education is the most common reason. Doctors don't inform patients or patients do not ask questions.

Polypharmacy in of itself is not problematic. Consider, for instance, a patient with type 2 diabetes and existing coronary heart disease who has received a recent coronary stent for myocardial infarctiion. It is not unreasonable or uncommon for this patient to be on 6 to 9 medications to reduce his or her long term risk for diabetes complications and secondary coronary events. In fact, strict adherence to national treatment guidelines for this patient will result in a minimum of 6 concurrent prescription therapies.

Polypharmacy can, however, become problematic when negative outcomes occur. Polypharmacy has been shown to result in:

1) unnecessary and/or inappropriate medication prescribing
2) increased risk for drug interactions and adverse drug reactions
3) nonadherence
4) increased overall drug expenditures.

The prescribing of inappropriate medication often results in polypharmacy. For example, an 85-year old woman is prescribed Elavil® (amitriptyline) 50mg at bedtime for insomnia. Common side effects include constipation, urinary incontinence, dizziness, dry mouth, and dry eyes. To "treat" the side effects, a prescriber may prescribe

Senokot® for constipation, Ditropan® for urinary incontinence, and eye drops for dry eyes. Here, the prescribing of one therapy to treat insomnia results in a total of four medications.

Mark H. Beers, MD, a gerontologist, has been advocating the use of criteria-developed through consensus panels for identifying inappropriate use of medications. He states that "the use of a medication is appropriate if its use has potential benefits that outweigh potential risks". His first list was developed specifically with the frail elderly nursing facility resident in mind. In 1997, Beers updated his criteria to include medication inappropriate in all patients over 65 years old. Pharmacists can use both sets of criteria in prescription processing and drug regimen review to improve the pharmacotherapeutic regimens of their elderly patients.

Treatment of Polypharmacy

1. **Maintain an accurate medication and medical history.** Identify all medications, including any OTC therapies. Having a complete list of medications can deter a provider from adding on an additional therapy. Further, knowledge of a specific medication being used may explain a patient-specific symptom or complaint. For example, knowing a patient is on an opiod analgesic may explain why he or she has constipation. A complete history of the patient's medical condition also is important. Identifying the patient's medical history allows the pharmacist to identify inappropriately prescribed medications. For instance, metformin is not appropriate for patients with end-stage kidney disease.
2. **Link each prescribed medication to a disease state**. Each medication should match a patient's diagnosis. Any medication that does not match a diagnosis is potentially unnecessary, and an attempt to discontinue the medication should be made. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) is a not-for-profit (nongovernmental) organization. Its mission is to improve the safety and quality of care provided to the public through the provision of health care accreditation and related services that support performance improvement in health care organizations. JCAHO recognized this problem and instituted Medication Management Standard 3.10 in 2005, which states "*Only medications needed to treat the patient's condition are ordered".* This means that prescribers of accredited facilities (RWSIR is accredited by JCAHO) are required to write indications for all medications prescribed (or at least mention somewhere in the chart why the patient is taking that medication).
3. **Identify medications that are treating side effects.** The use of multiple medications leads to a higher risk of side effects. When side effects occur, additional medications can be initiated to treat the side effect. A common example includes the use of laxatives to treat the medication side effect of constipation. Other examples include:
   - **The use of sleeping meds** to treat insomnia caused by theophylline, prednisone & antidepressants
   - **Aricept® (Donepezil)** to treat cognitive impairment caused by obybutynin,/tolterodine, antihistamines, opiods, and benzodiazepines

   Discontinuing one drug that is causing a side effect can often lead to the discontinuation of several drugs.
4. **Initiate interventions to ensure adherence**. Using combination products (i.e., lisinopril/hydrochlorthiazide combination pill) will reduce overall pill number and potentially improve adherence. Other strategies include using generic options to reduce cost and using adherence aids such as pillboxes.
5. **Reconcile medications upon discharge from hospital or skilled nursing facility**. As mentioned above, a risk factor for polypharmacy includes recent hospitalization. The transfer of a patient from a hospital to his or her home is associated with adverse events and negative outcomes, most of which are related to changes in the patient's drug therapy during treatment in these facilities. Evaluating a patient's medication regimen and educating a patient upon discharge from a facility is likely to reduce duplicate therapy, inappropriate prescribing, and reduce unnecessary medication. JCAHO has recognized this and made medication reconciliation a 2005 National Patient Safety Goal for all accredited hospitals.

6. **Prevention.** The appropriateness of the medication for the patient and the potential for side effects must be considered. As the old adage goes, "an ounce of prevention is worth a pound of cure". Any drug that is unnecessary, inappropriate, or has a high likelihood for causing side effects that would require additional therapy should be avoided.

Role of Pharmacists

The role of the pharmacist in the prevention and treatment of polypharmacy differs depending on the health care setting. Long-term care pharmacists routinely evaluate drug therapy regimens in predominantly elderly patients. They adhere to federal regulations with the goal of reducing negative outcomes associated with polypharmacy. Hospital pharmacists review the complete and accurate list of the patient's medications, evaluate this list for drug therapy problems that arise when medications are discontinued and initiated during hospitalization. Community pharmacists play a vital role in polypharmacy by preventing the dispensing of unnecessary, inappropriate, and side effect-prone medication.

Role of Consumer

By being an informed consumer, you can help prevent polypharmacy. The following is a list of steps to help you get started:

1) The **most important** thing you can do is **get involved** in your healthcare. Studies show that you have better outcomes when you are involved. Don't be afraid to ask questions.
2) **Know the name and strength of the medications you take, their indications, side effects, and drug interactions.**
3) Buy generics whenever possible. When you start on a new medication, ask for samples. You may not be able to tolerate it and can change meds before you get a prescription filled.
4) Brown-bag it: take all your meds including prescriptions, over-the-counter (otc) meds, and dietary/herbal supplements with you when you go to the doctor's office or hospital. You can keep a list, but you have to constantly keep it up-to-date. Remember that otc's are medications and can interact with your prescription meds. The latest news reports have covered the potential interaction where Prilosec® (Omeprazole) decreases the antiplatelet effect of Plavix®(clopidrogel). With the majority of data suggesting this, patients thinking about buying OTC omeprazole might be wise to buy an histamine (H2) antagonist (Pepcid® or Zantac®) at this time.
5) Have someone (spouse, friend) go with you to the doctor. Two ears are always better than one!
6) Ensure dietary/herbal supplements are safe before taking. Long term efficacy has not been determined. The majority of data concerning these products are derived from small trials with poor study design. These so-called natural products are not regulated by FDA, and stronger data supporting their efficacy is needed. For now, look for the USP seal on the label. Only supplements bearing this mark have been verified by US Pharmacopeia that the bottle contains the ingredients listed on label; is free of harmful contaminants; will properly release into body, and was made using good safe manufacturing processes. To become "savvy supplement user", see these Websites:
7) *http://www.cfsan.fda.gov/~dms/ds-savvy.html*
   http://dietary-supplements.info.nih.gov
   http://nccam.nih.gov (1-888-NIH CAM)
   www.ftc.gov
8) Store meds in a cool, dry place; preferably someplace where you can remember to take them (on the kitchen table if you take meds with meals or at the bedside if you take at bedtime). Be sure to keep these meds out of the reach of small children.
9) Ask your pharmacy for flip-top lids if you have a hard time opening the child-resistant lids.
10) If you can't remember if you've taken your meds, try a med dispenser. You can fill them up weekly, and you know at the end of the day if you have taken them or not.

11) Expiration date: The date at which the manufacturer can no longer guarantee the full effect of the medication.
12) Be environmental friendly and avoid flushing and pouring discontinued/expired medications down the sink. Instead, mix meds in cat litter or coffee grounds and place them in the trash.

Different Forms of Therapy

Approximately 4 out of every 10 adults report the use of some type of complementary and alternative medicine (CAM). The most common forms include natural products, deep breathing exercises, meditation, chiropractic or osteopathic manipulation, massage and yoga. CAM use is complementary in nature and is used in conjunction with our conventional medicine. Unfortunately, the forms of CAM that have the best evidence of efficacy, such as acupuncture, have lower rates of use in the survey. The concerns about cost of a conventional therapy could inspire patients to consider CAM over standard treatments, especially given the current economic environment.

Remember, the most important step in preventing negative outcomes regarding polypharmacy is **getting involved** in your own healthcare. Become an informed consumer. All medications (prescriptions and over-the-counter) have risks as well as benefits. As a consumer, you must weigh the benefits vs. the risks carefully before taking. You must appreciate the power of medicine, the value of meds when used properly and the consequences when used improperly.. You have both the responsibility and the duty of learning about how to take each medication safely.

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Too Hot and Too Cold: Causes and Solutions

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Body Temperature Regulation

Body Temperature
- "Core" temperature
  - As warm-blooded creatures, we maintain a consistent internal temperature within 1 degree Fahrenheit in normal circumstances
- Surface temperature
  - The skin and sub-cutaneous tissue temperature is affected by environment

Normal Body Temperature
- Range of normal
  - From approximately 97 F to 99 F (oral measurement)
  - Fluctuates slightly during the day- diurnal variation
  - Temperature variations may be more pronounced in young people
- Minor variations from normal with extreme exercise, and environmental extremes
  - Temperature regulation not 100% effective or instantaneous

Regulation of Body Temperature
- Skin, subcutaneous tissues and fat act as a heat insulator
- Fat conducts heat 1/3 as readily as other tissues
- Insulation maintains internal body temperature, allowing skin to reflect external temperature

Heat Transfer from Core to Surface
- Blood vessels in the subcutaneous tissues transfer heat to the body surface
- Vessels can constrict, reducing blood flow and conserving heat
- Vessels may dilate, allowing a high rate of blood flow to the skin to dissipate internal heat

Heat Production
- Body metabolism produces heat
- The rate of heat production is affected by:
  - Basal metabolic rate
  - Muscle activity
  - Hormones
  - Neurotransmitters

Factors Affecting Basal Metabolic Rate
- Activity/ Exercise
- Digestion (specific dynamic action) of protein
- Age
- Thyroid hormone
- Sympathetic nervous system
- Male hormone
- Growth hormone
- Fever
- Climate
- Sleep
- Malnutrition

Heat Loss

- Radiation: heat radiates to and from the body in the form of infrared heat rays
- Conduction: direct transfer of heat from the body to other objects including air or water
- Convection: removal of heat by convection air currents
- Evaporation: 0.58 Cal of heat is lost for each gram of water that evaporates from the body
- Combination of methods increases efficiency

Heat Balance

- Rate of heat production equals rate of heat loss
- To maintain balance the nervous system can affect either rate of heat production and/ or rate of heat loss by activating various temperature control mechanisms

Role of the Nervous System

- The hypothalamus has heat-sensitive neurons that function as temperature sensors
- Activation of heat-sensitive neurons results in vasodilatation and sweating
- Pathways involved in cold response are found in the hypothalamus, midbrain and medulla
- Multiple feedback- feed forward loops exist

Body Temperature Reduction

- The hyopothalamus may decrease body temperature by:
  - Blood vessel dilatation through inhibition of the sympathetic centers
  - Increased rate of sweating
  - Inhibition of shivering and chemical thermogenesis
- Sweating
  - Sweat glands innervated by sympathetic cholinergic nerves
  - Sweat glands can also be stimulated by adrenergic neurotransmitters circulating in the blood
  - Sweating effectively uses conduction and evaporation to cool the body

Increasing Body Temperature

- The thermostatic mechanism of the hypothalamus can raise temperature by:
  - Skin vasoconstriction by increased sympathetic outflow
  - Pilo-erection
  - Increased heat production through shivering, sympathetic “chemical” excitation (occurs in brown fat) and thyroxine secretion

Detection of Cold

- Cold receptors in the skin, spinal cord, abdomen
- Skin has far more cold receptors than warmth receptors
- Reflex responses include:
  - Shivering to increase body heat production
  - Inhibition of sweating
  - Vasoconstriction in the skin

“Balance Point” Temperature

- Critical value above or below which the temperature control mechanisms are activated to bring temperature back to the balance point
- Original “set-point” term implies a unified control system
- Balance point is affected by temperature receptors in the hypothalamus, midbrain, medulla and peripheral signals

Changes in “Balance Point”

- Pyrogens raise the set-point of the hypothalamus
- Anti-pyretics (aspirin, etc) lower the “set-point”
- Neurotransmitters, hormones and medications may affect thermoregulatory neurons

Dysfunction of Temperature Regulation

What makes us “too hot” or “too cold”?

- Difference between core temperature and “balance point”
- Temperature control mechanisms overwhelmed by external temperature
- Dysfunction of temperature control mechanisms
- Peripheral temperature changes related to core temperature

Too Hot

- Heat Sensitivity
- Heat Intolerance: inability to be comfortable when external temperatures rise
- Hyperthermia: elevation of core body temperature
  - May lead to heat stroke

Causes of Heat Sensitivity

- High basal metabolic rate
- Excess body fat
- Thyroid/ parathyroid disorder
- Hormone changes: pregnancy, menopause
- Myelinopathies (i.e. multiple sclerosis)
- Stimulants: caffeine, amphetamines

Causes of Hyperthermia

- Increased body heat production
  - Overexertion
  - Fever: infection, cancer, auto-immune disease
  - Medications, chemicals and toxins
  - Metabolic disorder: hyperthyroid, parathyroid dysfunction
- Decreased sweating: dehydration, poor circulation, old age
- Decreased conduction: high ambient temperature
- Decreased evaporation: high humidity
- High body mass index- lower surface area in relation to mass

Drugs Associated with Hyperthermia

- MAO inhibitors
- SSRIs
- Amphetamines
- Tricyclic antidepressants
- Dextromethorphan (may be in cough medicine)
- Analgesics: aspirin, tramadol, demerol
- Antihistamines
- Cocaine

Polio-Related Causes of Heat Sensitivity

- Increased energy requirement to perform activities
- Decreased sweating due to sympathetic nerve dysfunction
- Lower peripheral capillary density

Too Cold

- Cold Sensitivity: Feeling cold or sensitivity to the cold
- Cold Intolerance: an abnormal sensitivity to a cold environment or cold temperatures
- Hypothermia: abnormally low core body temperature

Causes of Cold Sensitivity

- Normal genetic variant
- Normal aging
- Stress
- Low body fat
- Low basal metabolic rate
- Raynaud’s phenomenon
- Poor circulation due to cardiovascular disease
- Anemia
  - Iron deficiency
  - Thiamine deficiency
- Thyroid / Hypothyroid disorder
- Metabolic disease
- Malnutrition

Causes of Hypothermia

- Decreased Shivering
  - Normal aging
  - Hypoglycemia
  - Hypothalamic Dysfunction
  - Spinal cord injury
  - Drug effects
- Decreased vasoconstriction
  - Spinal cord injury
  - Hypothalamic dysfunction
  - Drug effects
- Behavioral dysfunction
  - Psychiatric disorders
  - Seasonal affective disorder
  - Drug effects
- Decreased endogenous heat production
  - Sepsis
  - Liver failure
  - Hypoglycemia
  - Hypothyroidism
  - Shock
  - Drug effects

Drugs Associated with Hypothermia

- Alcohols: behavioral, vasodilatation
- Beta-blockers: decreased cardiac output, altered fat and glucose metabolism
- Alpha agonists (Clonidine): hypothalamic depression
- Cholinergic agents (cholinesterase inhibitors): sweating, impaired glucose metabolism
- Neuroleptic drugs (phenothiazines, piperidines, butyrophenones): hypothalamic depression
- Sedative hypnotic drugs (barbituates, meprobamate, chloral hydrate): hypothalamic depression, behavioral

Polio Related Causes of Cold Sensitivity

- Reduced peripheral circulation related to muscle activity
- Immobility of limb
- Lower capillary density
- Decreased basal metabolic rate
- Polio involvement of midbrain and medulla
- Sympathetic nerve dysfunction

Management of Temperature Sensitivity

- Medical evaluation
- Evaluate medications for potential side effects
- Avoid:
  - Smoking- impaired circulation
  - Caffeine- causes vasoconstriction
  - Alcohol- causes vasodilatation (increasing heat loss), slows metabolism
- Optimize body mass index
- Good hydration and nutrition
- Regular exercise program to improve peripheral circulation and efficiency of temperature control mechanisms
- Biofeedback
- Environment Control
  - Climate considerations
    - Temperature, humidity, wind
  - Indoor climate control
    - Drafts/ fans
    - Special programs through gas/ electric companies to ensure ability to heat and cool home adequately
- Proper clothing
  - Do not wear constricting clothing or shoes
  - Wear several layers of loose clothing
  - Insulating fabric/ materials: silk, wool, polypropylene, fleece
  - Cover head, neck, hands, feet
  - Use a blanket or throw when sitting still
  - Camping/ sporting good stores and websites are good resources

Resources

Because heating costs are high, the U.S. Department of Health and Human Services has funds to help low-income families pay their heating bills. For more information, contact the Low Income Home Energy Assistance Program (1-866-674-6327) or the Eldercare Locator (1-800-677-1116).

The NIA has free information about hypothermia. To order the fact sheet, *Hypothermia: A Cold Weather Hazard*, or the brochure, *Stay Safe in Cold Weather*, call toll free 1-800-222-2225. *Hipotermia: El Peligro de las Bajas Temperaturas* is also available. These and other free publications on healthy aging can be downloaded from the NIA Web site at www.nia.nih.gov

Warm Clothing
http://www.wintersilks.com/
http://www.sierratradingpost.com/
http://www.llbean.com/?qs=3009633
http://www.cabelas.com/

When Are Trachs an Option?

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Home Mechanical Ventilation (HMV) has saved the lives of many polio survivors and individuals with other neuromuscular conditions. Its benefits far outweigh its inconveniences and the psychological adjustments of needing a machine to assist with breathing. These include 1) Improving quality of sleep, daytime functioning, and quality of life; 2) Increasing lung functioning, energy, muscle strength, longevity; and 3) Strengthening the immune system and reducing risks of respiratory illnesses.

We believe that non-invasive ventilation (NIV) is the most appropriate form of ventilation for most people with neuromuscular respiratory conditions. However, some vent users have opted to use a tracheostomy (trach). Deciding to use a trach is a complex issue. In the following pages we offer information and assessment tools to explore the option of using a trach when NIV ceases to provide enough of respiratory support to function effectively. While using a trach is not suitable and affordable for every vent user, we consider it a valid option when NIV no longer meets a person's needs. Each vent user needs to decide whether NIV or a trach suits his or her medical conditions and lifestyles best.

"I would definitely prefer to use non-invasive ventilation (NIV) rather than a trach if NIV enabled me to breathe adequately and function effectively. However, after using NIV for over 22 years, I had increasing breathing problems during the day when I was off of my volume ventilator. Then, in 2006, after an emergency surgery and respiratory failure, I could no longer breathe off my ventilator. I agreed to receive a trach to save my life.

With the trach, I currently am able to function off the ventilator during the day for extended periods. The airway hole allows me to inhale and exhale room air that I need to breathe easily. Since I still am unable to breathe just through my nose, I would need to be connected to NIV all day if I didn't have a trach. Even then, I am not sure that NIV would adequately ventilate my lungs. When I used NIV, I had difficulties with air leaks and air traveling to my stomach, exacerbating my IBS condition. I used numerous interfaces, including custom made masks. Despite NIV's advantages, I prefer the mobility and freedom that a trach currently affords me. I hope I will grow strong enough to return to using NIV. But if not, I will continue to depend on a trach to keep me alive and able to experience what gives meaning, satisfaction, and joy to my life." ***Linda Bieniek, Polio Survivor & Ventilator User: NIV 22 yrs, Trach 3***

"It is essential that every individual have a knowledgeable ***health advocate*** *who understands their condition, past and recent experiences, personal preferences, and wishes. This advocate must be a person educated in the clinical need…..They should be kept abreast of new developments and usually should accompany the person in person when they access the health system, health facilities, use any health resources."* ***Allen Goldberg, MD, PHI/IVUN Honorary Board Member,*** served as the health advocate for Margaret Pfrommer, a polio survivor friend who was paralyzed from her neck down and used NIV until her final years when she transitioned to using a trach.

Obstacles to Using Home Mechanical Ventilation (HMV) include:

1. **Lack of access** to knowledgeable healthcare professionals: pulmonologists, respiratory therapists, Emergency Room and hospital staff, and home health providers as well as equipped facilities in remote areas and developing countries.
2. **Psychological factors**: such as losses of control, independence, mobility, quality of life, self-esteem; relationship, intimacy, and role changes; fears of institutionalism, isolation; anxiety and PTSD triggers; depression, and dissociation.

Benefits and Disadvantages of Trachs and Non-Invasive Ventilation

Tracheostomy		Non-Invasive	
Benefits	**Disadvantages**	**Benefits**	**Disadvantages**
• Saves lives when person cannot breathe sufficiently on NIV & has dangerous blood gas levels & minimal vital capacity	• **See “Obstacles” above on psychological issues.**	• Significantly lower out-of-pocket costs for assistance & supplies	• **See “Obstacles” above on “access, psychological issues.”**.
• Provides more direct and stronger ventilation to the lungs • Reduces problems with interface leaks • Reduces gastrointestinal problems since air is not traveling into the stomach & causing bloating	• Increases out-of-pocket expenses **significantly** for assistance & supplies. • Legislation often limits care to RN & RT professionals with high hourly rates.	• Provides greater mobility if only needed at nighttime & limited daytime hours	• Interface air leaks limit the volume of air into the lungs • Finding an interface (mask, mouthpiece) that fits properly & comfortably
• Provides breathing through inner cannula while off the vent during daytime periods rather than needing to use non-invasive vent continuously	• Increases daily care needs: ➢ Personal assistance ➢ Suctioning ➢ Cleaning equipment	• Reduces risk of infections because airway is not exposed	• No alarms. Risk of tubing disconnections while asleep.
• Aids recovery of pneumonias: ➢ Suctioning access to mucous ➢ Direct pressure via Cough Assist	• May require a speaking valve to talk or may be unable to talk	• Less need for assistance if vent user is able to use arms & hands	• May reduce ability to see well with nasal or full face mask interfaces
• Alarms when equipment disconnects or pressure changes • Internal & external batteries may last 7-8 hrs	• Need for: ➢ Secretion management & humidity ➢ Extra equipment, supplies ➢ Back-up generator	• Provides greater independence & mobility, higher self-esteem	• 24/7 users may experience some difficulties speaking & eating with mouthpiece interface
•	• Possible risks of: ➢ Infections ➢ Bleeding from irritations ➢ Granulated tissue	• Smaller, lighter equipment increases ability to travel	• No back-up battery for emergencies.
•	• Reduces ability to live at home independently	•	• Need for back-up generator during emergencies

"*The cost of care and caregiver legislation and conditions become 'monumentally' more difficult if you have a trach (especially 24/7) and are trying to live in the community…the 'RN only' restrictions in many areas create a huge liability, unless you can take care of your trach yourself- especially the suctioning.*" ***Audrey King, Polio Survivor & Non-Invasive Ventilator User-- Used a Trach for 2 years***

"*When I got home from the hospital I did my own trach care….I had help when doing a complete trach change, once a month at first and now once every other month. ….I need to be suctioned, on average, about once a day. Sometimes I go a week between suctioning and sometimes I'll be suctioned two or three times in one day….*" ***Richard Daggett, Polio Survivor & Ventilator User with a Trach since 1984***

"*Since 2006, the difficulties of living with a trach have been: 1) infections and pneumonias; 2) costs for needing greater assistance; 3) increasing dependencies; and 4) loneliness when I was unable to talk (for months), and when I don't have enough energy to connect with others even by phone or computer. Yet, I have NO REGRETS about getting a trach.*" ***Linda Bieniek, Trach User***

Decide on Whether To Use a Trach Before An Emergency--Factors to Consider The questions in this table can help you identify your needs, available resources, and whether you can afford to live at home with a trach. Each topic is important and relates to the challenges of living with a trach.	**YES**	**NO**	**COMMENTS RESOURCES NEEDED**
Healthcare Resources Do you have access to knowledgeable, responsive healthcare professionals including a pulmonologist, home health care services, and an accessible medical center/hospital equipped to handle your use of HMV?			
Psychological Resilience Do you consider your life worth living? Do you have a purpose in life? Are you creative and resourceful in finding ways to fulfill your personal needs?			
Coordination of Care **Do you have an available, dedicated Health Advocate who understands your clinical conditions, needs, & preferences & will communicate with health professionals & oversee coordination of your care?** Do you have a dedicated supporter who will coordinate a communication network to provide you with information, suggestions, resources, support, greetings, and prayers?			
Daily Assistance: Are you capable of doing your own trach care? How much assistance will you need in addition to what you currently receive? Will you need 24/7 help? Do you have enough reliable assistants (family, friends, volunteers) to provide daily trach care, emergency assistance, & coordination of appointments with health professionals, home health providers, and suppliers?			
Financial Costs What costs will your health care insurance, government assistance, and/or long-term care policy pay for? What will your out-of-pocket costs total after reimbursements from health insurance and other sources? Can you afford the unreimbursed costs for personal assistance, supplies, and equipment? Will you be able to afford to continue living in your current arrangement or will you need to change it?			

Living Arrangement Will you be able to physically manage your current living arrangement--alone or with others? Can you adapt to living in government-funded housing or a nursing home if you cannot afford in-home care?			
Support Network: Do you have a strong network that will visit and assist you? Do you have meaningful relationships that you can depend on for emotional support? Do you stay connected with individuals & organizations through a phone & computer?			

"After experiencing the downsides of receiving a trach in an emergency situation without any prior planning, I highly recommend that vent users consider the following issues to help in making a rational decision about whether to use a trach in the short or long-term." ***Linda Bieniek, Trach User***

Explore Resources and Issues Related to Using a Trach

1. **Obtain information** about using a tracheostomy with HMV from:
    a. International Ventilators Users Network (IVUN). www.ventusers.org articles on NIV and trachs, *Resource Directory for Ventilator Assisted Living,* and *Home Ventilator Guide*.
    b. West Park Health Centre's e-learning modules: www.westpark.org www.ltvcoe.com/training_oelib_home.html.
    c. Ottawa Rehabilitation Institute's e-learning modules: www.irrd.ca/education.
    d. LISTSERVS' participants. See list in the *Resource Directory for Ventilator Assisted Living* on www.ventusers.org. Consider comments from individuals objectively since their attitudes differ for a variety of reasons.
2. **Consult resources** to gain perspectives and determine your sources of support—healthcare, financial and personal**:**
    a. Ventilator users, preferably who have used both non-invasive and invasive ventilation:
        i. Watch CHEST video of Audrey King describing her experiences adjusting to a trach. Contact mlederer@chestnet.org for a copy.
        ii. Obtain referrals from International Ventilator Users Network (IVUN): 314.534.0476. director@ventusers.org.
    b. Your pulmonologist to gain insights about the pros and cons given your conditions.
    c. Other pulmonologists who specialize in HMV. Obtain names from www.ventusers.org: *Resource Directory for Ventilator-Assisted Living* or from IVUN at 314.534.0475.
    d. Insurance carriers about your policy's eligibility and reimbursement provisions.
    e. Government and social service agencies to learn if you qualify for any services.
    f. Your support network to find out the time and assistance they can commit to provide.
3. **Assess the facts and opinions** you have obtained along with the following:
    a. "*Invasive and Non-Invasive HMV: The Benefits and Disadvantages*"
    b. Your answers to questions in "*Decide on Whether To Use a Trach Before an Emergency--Factors To Consider"* section.
4. **Decide** if you are willing and able to afford to live with a trach:
    a. For the short-term, during your recovery from an emergency?
    b. For the long-term, if you use NIV but your breathing worsens and you unable to function.
5. **Inform individuals in writing** of your decisions to accept or decline use of a tracheostomy:
    a. Designated Powers of Attorney for health care. Include instructions in your Living Will.
    b. The person who will serve as your "health advocate."
    c. The person who will serve as your "communication coordinator."
    d. Your health care providers and family/friends who may accompany you in emergencies.
    e. Professionals who can authorize submission of your decisions into a hospital/medical center's electronic records.
6. **Complete** a copy of the "***Take Charge, No Chances***" forms and give a copy to key individuals. Include your ventilator settings and emergency wishes. www.ventusers.org/vume/index.

In Response to Dr. John Bach's Assertion that "*Nobody with polio should have a tracheostomy tube for respiratory management – ever.*" Many of us know of, and admire Dr. Bach's understanding of physiology and work with HMV. While we have great respect for him and his dedication to his patients, we disagree with his assertion. Using NIV 24/7, as he does with individuals who have very low vital capacities, may not suit the lifestyles and preferences of all vent users. Richard Daggett, a Post-Polio Support Group Leader, responded to Dr. Bach's claims. A few of his comments are condensed below:

"Polio survivors differ and need medical care based on each individual's needs and not on a preconceived idea of what is best for "everyone."…Dr. Bach contends that, 'trach tubes are foreign bodies. They contain very bad bacteria that go into the lungs.' Yet instruments such as pacemakers and coronary stents are also 'foreign bodies' that save lives and enable individuals to live actively.

I have had a trach since 1984. It was my decision. I breathe easier and manage colds much better. No doctor told me, "You need a hole in your neck." I asked for the trach. Certainly a trach is not for everyone. Non-invasive respiratory assistance should be tried first. I firmly believe, however, a trach is a viable option for some."

Richard Daggett, Trach User since 1984

A recently published article titled, "*Quality-of-Life Evaluation of Patients with Neuromuscular and Skeletal Diseases Treated With Noninvasive and Invasive Home Mechanical Ventilation*" concluded:

> *"Patients receiving HMV reported a good perceived health, despite severe physical limitations. The patients with post-polio dysfunction and the patients with scoliosis treated with tracheostomy perceived the best health, compared with NIV for this diagnosis."*

Trach? Or Not?

Brenda Butka, MD
Vanderbilt University School of Medicine, Nashville, Tennessee

Why breathe?

"In with the good, out with the bad"
Pull in oxygen: fuel
Push out carbon dioxide: waste product

Breathing: The System

- Lungs: transmit oxygen/carbon dioxide
- Muscles: bellows to push/pull
- Airways: gas transit
- Brain: controller

Muscle weakness

- Lungs usually ok
- Not enough ventilation
- Poor cough

Consider

- Secretion management
- Ventilatory support

Secretion management = Cough

- Deep breath
- Strong exhalation
- Close glottis

Deep breath = volume

- Problem if VC less than 50%
- Supplement by
  - IPPB
  - Stacked ambu
  - Cough assist
  - Breath stacking

Exhalation

- Peak flow < 5 LPS
- Supplement
  - Manual assist cough
  - Cough Assist

Close Glottis for Cough

- Vocal cord problems hard to fix
- Tracheostomy
  - Cap
  - Passy-Muir valve

Secretion Management

- Cough Assist
- Suction
- Vibrating vest
- Flutter valve
- IPV

Consider

- Secretion management
- Ventilatory support

Ventilator support

- Invasive
- Noninvasive

Tracheostomy: WHY?

- Bulbar involvement
- Decreased compliance: “stiff” lungs
- Secretions
- Airway obstruction
- Failure of NIV

Tracheostomy Ventilation

- More secure
- Vents have batteries, alarms
- Usually can eat/talk
- Not necessarily 24/7
- Better interface for secretion management
- Caregiver stress/fatigue
- May not have long-term care options on vent

Ventilator support

- Invasive
- Noninvasive

Noninvasive

- Usually Bipap with backup rate
- Can use volume ventilator
- Negative pressure: cuirass or “lung”
- Belt
- Rocking bed

Noninvasive interfaces

- Fullface mask
- Nasal
- Oral
- Mouthpiece

Noninvasive

- Can be 24/7
- Speech/eating unimpaired
- Airway not as secure
- Doesn’t work if lungs are stiff
- Secretion management more difficult

Explanations and Demonstrations of Equipment

Kristy McClellan, RRT, Vanderbilt Stallworth Rehabilitation Hospital
Nashville, Tennessee

1. Types of Trachs
2. Types of Ventilation used with trachs (Bi-Pap, volume)
3. Types of Suctioning
4. Passy Muir Valve
5. Cough Assist Machine
6. Respiratory Therapist's role in managing ventilation and use of a trach

Trach or not?

You're not like anyone else …

SESSION S3

Post-Polio Research: Progress, Possibilities and Problems

Prof. Kristian Borg, MD, PhD, Karolinska Institutet, Stockholm, Sweden

Frans Nollet, MD, PhD, Academic Medical Center, University of Amsterdam, Amsterdam, The Netherlands

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Rahnuma Wahid, PhD, Manager Analytical Immunology, Sanofi Pasteur, Swiftwater, Pennsylvania

Post Polio Research at Karolinska Institutet

Kristian Borg MD, PhD, Gunilla Östlund PhD, Lars Werhagen MD,PhD, Eva Melin MD, Katarina Skough reg PT; Tae Du Jung, M.D, Henrik Gonzalez, MD, PhD
Division of Rehabilitation Medicine, Department of Clinical Sciences, Karolinska Institutet.
Danderyd Hospital, Stockholm, Sweden

From the beginning of the 1980:s our research group has performed clinical, pathophysiological and interventional studies in the field of post-polio. The group has produced three dissertations and has three planned dissertations in the coming years. The research was in the first phase concentrated on neurophysiological and muscle morphological studies with a focus on consequences of compensatory mechanisms in overused muscles. During the last decade the research has been focused on immunology and intervention with immune modulation with intravenous immunoglobulin (IVIG) and on finding a biomarker in patients with post-polio syndrome (PPS). Furthermore, we have studied different aspects of quality of life in patients with fatigue and pain.

Overuse of muscle and compensatory mechanisms

Data from earlier studies from our group support the hypothesis that PPMD is due to denervation. Neurophysiological studies have shown signs of ongoing denervation which also is supported by findings of atrophic muscle fibres in muscle biopsies (Borg et al 1988, Borg and Henriksson 1991, Borg and Edström 1993). Macro-EMG studies have shown that the motor units in PPS patients are 5-10 times larger than normal indicating reinnervation by means of collateral sprouting (Tollbäck et al 1993). In other studies the largest motor units have been shown to decrease over time suggesting a failing reinnervation in PPS patients. Thus, the new or increasing muscle weakness in post-polio patients may be due to a denervation-reinnervation process that have reached its upper limit, i.e. the insufficiently compensated denervation leads to muscle weakness (Borg 1996).

Reinnervation is probably the most powerful compensatory mechanism. However, there are other compensatory and adaptive mechanisms in muscles of PPS patients leading to an increase of the contractile tissue or changing the contractile properties. Muscle fibre hypertrophy and an increased frequency of type I muscle fibres have been reported in the anterior tibial muscle (Borg et al 1988, Borg et al 1989) and Tollbäck (1995) found that the overused motor units had lost their differentiation and were activated in an all-or-none fashion. The motor unit properties were changed towards a uniform type with intermediate properties favouring strength before endurance and driven into contractile fatigue more easily than normal units (Tollbäck 1995).

In a double-blinded placebo controlled study study muscle training with substitution of enzyme Q-10 was evaluated. The exercise resulted in an increase of muscle power but there was no difference between Q-10 and placebo (Skough et al 2008). A rehabilitation programme based mostly on physiotherapy has been evaluated and found to increase quality of life mostly for mental but also for physical domains (Jung et al 2008a).

Immunological aspects of PPS and outcome of immunmodulatory treatment

Several authors have suggested that an immune response could be one explanation for PPS. In some studies an ongoing inflammatory process in the spinal cord of PPS-patients and oligoclonal bands in CSF have been detected. When evaluating cytokines in cerebrospinal fluid (CSF) of PPS patients we found an increase of cytokines, Il-4, TNFa and IFNg, (Gonzalez et al 2002). The levels were in the same range as those found in Multiple Sclerosis (MS), a well-known neuroinflammatory disorder. In a pilot study a down-regulation of the cytokine levels was seen after intravenous treatment with immunglobulins (IVIG), (Gonzalez et al 2004). This was followed by an increase of muscle strength as well as quality of life, especially for vitality (Kaponides et al 2006). This was confirmed in a randomized, multi-centre and placebo-controlled study (Gonzalez et al 2006) in which an increase of muscle strength as well as quality of life for vitality and general health was found. Decrease of the cytokine levels and the clinical effect lasted for one year (Gonzalez et al 2009a). After 2.5 years the cytokine levels were back to the levels seen before IVIG treatment and the clinical effect had vanished (Gonzalez et al 2009b). In an open clinical study Werhagen et al (2009) found that around 2/3 of 64 PPS patients had a decrease of pain after IVIG treatment.

In order to analyze the occurrence of systemic inflammatory changes muscle biopsies were studied applying more modern immuncytochemical techniques. We were able to find minor signs of inflammation in some of the PPS patients (Melin et al 2009). An increase of serum lipids have been reported in PPS patients. One might speculate that this is due to a systemic inflammatory process. However, we were not able to find a decrease of serum lipids after IVIG treatment (Melin et al, personal communication) and we are now comparing data from PPS patients with normal data in order to evaluate if there is a serum lipid increase in PPS patients.

Biomarkers for PPS

In a recent published study (Gonzalez et al 2009c) proteomics were performed on CSF from PPS patients. A highly predictive and disease-specific differential expression was found in five proteins. The findings provide argument for an ongoing nervous tissue damage in PPS and the proteins are also involved in apoptosis. Further studies are performed in order to correlate these findings to clinical parameters in order to evaluate the clinical significance of the different proteins as biomarkers for PPS. The possibility of a connection with spinal muscular atrophy was disclosed by a normal SMN gene finding (Bartholdi et al 2000). However, other potential genetical factors should be explored.

Pain, fatigue and quality of life in PPS

During the acute polio infection, the patients had signs of meningitis and there has been a discussion of whether or not the increased tiredness and mental fatigue may be due to an affection of higher CNS functions. In a few studies around half of the PPS patients had signs of affection of cognitive functions. We have not been able to reproduce this finding in a Swedish PPS population (Östlund et al 2005).

In contrary to the common belief, PPSpatients perceive less pain and vitality increases with increasing age (Östlund et al 2008). Furthermore, an increase of quality of life with increasing age and with male gender was found when performing SF-36 questionnaire in a large PPS cohort (Jung et al 2009a). It was also found that vitality in PPS patients was mostly of a physiological character in PPS patients and that mental fatigue was not a prominent feature(Östlund et al 2008). We have also been able to identify a subpopulation of PPS patients that were extremely fatigued (Östlund et al 2009). This group of patients were younger than the rest of the PPS patients and a thorough psychological analysis is now being performed. Analysis of pain in PPS patients showed that approximately 10% of the patients had neuropathic pain (Werhagen et al 2008). When neuropathic pain was present there was always a concomitant disorder for example lumbar disc hernia. Neuropathic pain was in most cases relieved by operation or medication.

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Summary of Post-Polio Research at University of Amsterdam

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The research on post-polio syndrome in Amsterdam started in 1989 and was initiated by professor Marianne de Visser, neurologist. From that time on increasing numbers of Dutch patients with post-polio syndrome came to Amsterdam and were also seen in the Department of Rehabilitation. In 1993 funding was obtained for a PhD research project of Frans Nollet. Since then post-polio research has continued in Amsterdam, led by Marianne de Visser, Anita Beelen and Frans Nollet, resulting in 27 peer reviewed scientific papers up till now. PhD theses were written by Barbara Ivanyi in 1999, Frans Nollet in 2002, Herwin Horemans in 2005 and Merel Brehm in 2007. At present 3 PhD students are doing research Janneke Stolwijk-Swüste, Fieke Koopman and Irene Tersteeg and a fourth one will start soon. What has been studied so far and what is presently being studied?

Research has been focused on clinical studies. Some results are summarized according to the topics that have been studied over the past years and can be categorized as:
I - epidemiological and longitudinal studies
II - diagnostic studies
III – physiological studies
IV- intervention studies
V - methodological studies

Epidemiological and longitudinal studies
Polio victims from the last large epidemic in The Netherlands in 1956 with almost 1800 cases were studied 39 years later. In this population-based study among 260 respondents almost 60% experienced signs of new weakness, increased disabilities and handicaps and diminished health-related quality of life. The use of devices and adaptations had increased.(8,12)
A cohort of 103 polio patients was followed for six years. 27 of them had stable polio and 76 post-polio syndrome.(7,14) It appeared that health-related quality of life of the patients with PPS was lower compared to the stable functioning polio individuals. Over the years physical functioning did not change much. However, it appeared that the severity of paresis at baseline was a prognostic factor for decline in physical functioning in six years. These results supported the concept of overuse, that a (slow) decline in muscle mass, as a late effect of polio, may lead to a decline in physical functioning as the reduced muscle capacity becomes less able to meet the demands of daily physical activities.

In a systematic review of the literature we concluded that so far no conclusions can be drawn from the literature with regard to the functional course or prognostic factors in late-onset polio sequelae.(23) The rate of decline in muscle strength is slow, and prognostic factors have not yet been identified. Long-term follow-up studies with unselected study populations and age-matched controls are needed, with specific focus on prognostic factors. Therefore we are presently conducting a longitudinal study involving 168 polio individuals.(26) This study focuses on the effects of aging and co-morbidity on functioning over time. Individuals ranging in age between 45 and 85 have been included and in contrast with many other studies, co-morbidities are not excluded but its influence on the time course is studied as this reflects what happens in reality with aging. At the moment the participants in the study have been followed for 5 years. Some results have been published. Age and co-morbidities were found to be negatively associated with physical functioning and physical independence. The influence of these factors on the changes over time are being analyzed at present. More publications from this cohort-study will follow in the next years.

Diagnostic studies

The value of muscle computed tomography (CT) was studied. It was shown that muscles of post-polio patients experiencing new muscle weakness showed significantly more CT scan abnormalities compared with stable post-polio patients.(5) Muscle CT scan evaluation was considered a useful adjunct to muscle strength assessment and is now routine procedure in clinical practice. Furthermore, sleep complaints were inventoried. It appeared that up to half of post-polio patients reported complaints of disordered sleep, which was likely to influence daytime functioning. This was not further analyzed.(4) At present we are doing research on this in the aging study in collaboration with pulmonologists form the Center for Home Ventilation in Utrecht.

Physiological studies

Aspects of muscle function and exercise capacity were studied. It appeared that exercise capacity of polio individuals was mainly determined by the available muscle mass. No convincing evidence as found for a poor cardio respiratory condition. Results were comparable to normally active healthy controls.(11) We confirmed reports from others that polio individuals, especially those with post-polio syndrome may have difficulty with activating their muscles and are thus not fully able to recruit the available capacity.(13, 19) A clinical relevant finding is that the energy cost of walking is directly related to the severity of polio residuals.(24) This implicates that in case of two severely affected legs walking may cost twice (or even more) energy as compared to healthy people. Together with a reduced muscle mass this implies that ‘one has to do more with less’ substantiating the concept of overuse as a major cause of post-polio complaints. However, it appeared that only those individuals with severely reduced walking ability, reduced their walking activity in daily life.(22)

Intervention studies

In 2003 we reported a study on the effects of pyridostigmine (a drug that improves neuromuscular transmission) on fatigue, muscle strength and functioning in post-polio syndrome.(15) Unfortunately, we found no effect, which was in line with the results published earlier by Trojan et al. Our hope was that an effect could be found with different outcomes in polio individuals with proven neuromuscular disturbances.(10) However, this was not the case. Since, some limited effects were found, a potential benefit of pyridostigmine can not entirely be ruled out. However, that would require another study, accounting for individual differences in drug uptake. At present no such study is undertaken.

Another area of interventions is innovation and biomechanical optimization of custom-made leg braces. We demonstrated that the energy cost of walking can be reduced substantially by improving braces.(27) A chapter on state-of-the-art carbon composite orthoses for post-polio syndrome was written for the latest edition of the Atlas of Orthoses and Assistive Devices by the American Association of Orthopedic Surgery issued in 2008. At the moment, a grant has been obtained to write a clinical prescription guideline. Research on the innovation of braces is ongoing in collaboration with orthopedic technicians and industry.

Methodological studies

In scientific research it is important to investigate the measurement properties of the instruments that are applied: questionnaires, time scored tests, strength tests, (electro)physiological measurements and so on. A number of papers have been published in this area. It appears that strength measurements with a hand-dynamometer, but also in a fixed chair-dynamometer show large variations and are not very sensitive to detect small changes over time in individuals.(9,19) This implies that it is not easily possible to conclude that strength has really declined in evaluating a person with post-polio syndrome over time. It appears that walking tests and measurements of energy consumption are better able to detect individual changes, although the sensitivity to detect change is less in polio individuals than in healthy controls.(21,24) In a recent paper, we recommended the Medical Outcomes Study Short Form 36 scale Physical Functioning and a 2-min walk test at self-selected speed to be used as core qualifiers for physical functioning, the major increasing disability in late-onset sequelae of poliomyelitis, to assess perceived physical performance and walking capacity in research and clinical practice.(29)

Research in progress

At present we are following up the cohort that is focusing on aging and co-morbidity. These studies are being done by Janneke Stolwijk-Swüste and Irene Tersteeg and supervised by Anita Beelen.

Another study is an intervention study to reduce fatigue and improve functioning. Two different strategies are being investigated physical exercise and a cognitive behavioral approach. This study is part of a larger project involving also other neuromuscular disorders, coordinated by senior-researchers Anita Beelen and Kimi Uegaki. This study is being done by Fieke Koopman and a second PhD student will be involved.

Finally, studies are ongoing regarding orthotic devices and clinical guidelines involving senior-researchers Merel Brehm and Carine van Schie.

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Summary of Recent Post-Polio Research at the Montreal Neurological Institute and Hospital

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We have completed and published several clinical research studies of relevance to post-polio patients over the last few years. Our studies have focused on pathophysiology, on fatigue, and on osteoporosis.

The cause of post-polio syndrome (PPS) is still unclear. Several hypotheses have been proposed including distal degeneration of enlarged post-polio motor units which develop during recovery from paralytic polio, motor neuron loss, normal aging, overuse, disuse, and immunological mechanisms. Gonzalez and co-workers (2002) reported increased mRNA levels of pro-inflammatory cytokines (signaling molecules) in the cerebrospinal fluid (and not the blood) of 13 PPS patients compared to normal controls. We have extended these findings by measuring the actual levels of several pro-inflammatory markers in the blood of 51 PPS patients and comparing them to 26 healthy controls. Another aim of the study was to evaluate the association of elevated inflammatory markers with several clinical parameters including muscle strength, fatigue, and pain. We found that the levels of several inflammatory markers (TNF-α, IL-6, and leptin) were increased in the blood of PPS patients compared to normal controls. Increased levels of TNF-α were associated with pain, specifically muscle pain. The reason for the increased inflammatory markers is unknown, but our findings indicate that inflammation may play a role in the ongoing PPS disease process.

We have also been interested in the area of fatigue in PPS and post-polio patients. Fatigue occurs in most PPS patients and is usually reported as the most disabling symptom. Two studies have been completed. The first was concerned with sleep disordered breathing in fatigued post-polio clinic patients and the second with biopsychosocial correlates of fatigue.

Sleep disordered breathing is the general term used to describe different types of breathing disorders during sleep. Three types of breathing disorders during sleep have been described: obstructive, central, and mixed apnea and hypopnea. Obstructive sleep apnea and hypopnea is characterized by repeated episodes of upper airway collapse during sleep, despite attempts at breathing. This can cause reduced blood oxygen levels during sleep and fragmented, poor sleep. These difficulties can lead to daytime fatigue and somnolence (sleepiness), as well as a number of neurocognitive difficulties (such as problems with attention and concentration) and medical difficulties. In the general population daytime sleepiness and fatigue can improve dramatically with treatment such as nasal continuous positive airway pressure (CPAP). Central apnea is characterized by cessation of airflow without attempt at breathing. Mixed apnea is a combination of the two. The aim of our study was to determine the frequency, predictive factors, and symptoms predictive of sleep disordered breathing in fatigued post-polio clinic patients. The study was a cross-sectional study involving a chart review of 590 post-polio clinic charts. 98 patients were included and all had a complete overnight polysomnogram (sleep study) in a sleep laboratory, 98% in the same laboratory. The gold standard for the diagnosis of sleep disordered breathing is in-laboratory, technician-attended, complete overnight polysomnography. An apnea-hypopnea index (AHI) was calculated. AHI is the total number of sleep related events per hour of sleep, and is used to assess the severity of sleep disordered breathing. The frequency of sleep disordered breathing was 65% (AHI≥5) and 50% (AHI≥10). The most common type was obstructive sleep hypopnea, present in 86% of patients with sleep disordered breathing. Most patients had mild (43%, AHI 5 to 15) or moderate (42%, AHI 15 to 30) sleep disordered breathing. A smaller proportion had severe sleep disordered breathing (16%, AHI > 30). Age, sex, age at acute polio, time since acute polio, weakness and respiratory difficulties at acute polio, speech and swallowing difficulties at acute polio and at evaluation, body mass index, pulmonary function measures, alcohol use, sedative drug use, smoking, fibromyalgia, kyphoscoliosis and scoliosis and ear/nose/throat surgery were not predictive of sleep disordered breathing. Snoring was more common in subjects with sleep disordered breathing. We conclude that sleep disordered breathing is very common in fatigued post-polio clinic patients referred for sleep evaluation. Obstructive hypopnea was the most common type. Snoring was the only clinical symptom that tended to predict sleep disordered breathing. Based on our results, we recommend that all post-polio patients with daytime fatigue and somnolence atypical for PPS undergo evaluation for sleep disordered breathing.

Our second study of relevance to fatigue was concerned with the development of biopsychosocial models for fatigue in PPS. Our aim was to determine the biopsychosocial correlates of general, physical, and mental fatigue in PPS, by measuring the additional contribution of potentially modifiable factors after accounting for important non-modifiable disease-related factors. 52 ambulatory PPS patients were included. Fatigue was assessed with the Multidimensional Fatigue Inventory (MFI) which assesses fatigue on five subscales (General Fatigue, Physical Fatigue, Reduced Activity, Reduced Motivation, and Mental Fatigue) and the Fatigue Severity Scale (FSS) which assesses fatigue in medical and neurological disease. We were concerned with general, physical, and mental fatigue because all three types of fatigue are reported in patients with PPS. Potential correlates for fatigue that we considered were disease-related factors (acute polio weakness, time since acute polio, PPS duration, muscle strength, pain, forced vital capacity, maximum inspiratory pressure, maximum expiratory pressure, body mass index, disability, fibromyalgia), behavioral factors (physical activity, sleep quality), and psychosocial factors (depression, stress, self-efficacy). Multivariate regression models were calculated for MFI General, Physical, and Mental Fatigue and for the FSS. Age-adjusted multivariate models with non-modifiable factors were first calculated. Then, age-adjusted models were calculated by determining the additional contribution of potentially modifiable variables while keeping the previously identified non-modifiable variables in the models. We found a different pattern of variables to be associated with general, physical, and mental fatigue. In multivariate models, correlates of general fatigue included disease-related and psychosocial factors. Correlates of physical fatigue were disease-related and behavioral factors. A correlate of mental fatigue was a psychosocial factor. A portion of fatigue could be explained by potentially modifiable factors. Because we identified several potentially modifiable predictors for both general and physical fatigue, our results suggest that an interdisciplinary rehabilitation team management program that can address several contributors to fatigue would likely be most useful in managing these fatigue types.

We have also been interested in the area of osteoporosis in post-polio clinic patients. Osteoporosis is a progressive skeletal disorder characterized by low bone mineral density that results in bone fragility and an increased tendency to fractures. Weakness is a risk factor for osteoporosis. Osteopenia is a decrease in bone mineral density and can be a precursor of osteoporosis. The aim of our study was to identify the frequency of osteoporosis at the hip and lumbar spine in a post-polio clinic population and to evaluate the association of muscle strength in the legs and other possible contributors contributing factors to osteoporosis with bone density results at the hip. The study was cross-sectional involving a chart review. 379 charts were reviewed and 164 patients were included. Most bone densitometries were performed at the same center with assessments at the hip and lumbar spine. Muscle strength was evaluated by manual muscle testing during a clinic neurological examination. The frequency of osteoporosis at the hip and lumbar spine was 32% and 10% of men, 9% and 6% of pre-menopausal women, and 27% and 11% of post-menopausal women. In a logistic regression multivariate model, the presence of osteoporosis at the hip was significantly associated with strength sumscore in the same leg in which the bone density was performed after adjusting for other important risk factors (age, body mass index, time since polio). We conclude that osteoporosis occurs commonly at the hip in post-polio clinic patients and that hip bone density is related to reduced muscle strength in the same leg. Based on our results, we recommend that all post-polio patients be evaluated for osteoporosis at both hips (or less preferably at the hip of the weaker leg) and at the lumbar spine.

Our studies had several limitations that were discussed in detail in the original publications. All studies summarized above were cross-sectional. Because of this, the temporal relationships and causal effects of the associations observed are unknown. In addition, our study of biopsychosocial models for fatigue in PPS had a relatively small sample size for this statistical technique. A larger sample size could have allowed us to find other contributors to fatigue in multivariate models.

In conclusion, we recommend that all post-polio clinic patients be evaluated for osteoporosis, and that all post-polio patients with fatigue or somnolence atypical for PPS be evaluated for SDB. Both disorders occur commonly in a post-polio clinic population. An interdisciplinary team approach may be best for management of several contributors to general and physical fatigue, but further randomized, controlled studies are necessary. Our finding of raised blood inflammatory markers in PPS, together with results from other research teams, prompt further prospective evaluation of the role of inflammatory mediators in the etiology and symptomatology of PPS.

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Regulatory T cells as a Biomarker of Post-Polio Syndrome

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There are large numbers of polio survivors today who contracted acute paralytic poliomyelitis prior to the advent of widespread vaccination programs against poliovirus (PV). What is under appreciated is the fact that polio survivors are many years later at risk of developing new neurological deterioration, a condition recognized in the late 80's as post-poliomyelitis syndrome (PPS). PPS is a slowly progressive disease in individuals previously affected by paralytic poliomyelitis that is characterized primarily by new muscle weakness and atrophy. Diagnosis of PPS is time-consuming and complicated by the need to rule out other diseases that could explain the new symptoms. The ability of a physician to diagnose a specific disease can be significantly aided by the availability of one or several disease biological markers (termed biomarkers). No biomarker(s) has been identified for PPS as yet that could assist in providing a definitive, easy and rapid diagnosis.

Disease biomarkers are measures of biological parameters indicative of a disease process. They are useful because they can assist in diagnosis or provide a means of monitoring the disease as it progresses and the effectiveness of different therapies. The study conducted at the University of Arkansas for Medical Sciences (UAMS) was, therefore, designed to answer a simple question: Are there signs or changes in the immune system (that is an immunological signature) that can be linked to Post-polio Syndrome (PPS)? If so, these changes in the immune system could be potentially used as a biomarker to diagnose PPS quickly and efficiently and to possibly provide clues as to the causes of PPS.

In this study there were 3 groups of individuals – (1) healthy individuals who never had disease associated with poliovirus and were vaccinated with the polio vaccine, (2) stable polio survivors, who suffered from poliomyelitis and may have had the vaccine but currently do not have symptoms associated with PPS, and (3) individuals with PPS. The goal was to determine whether the types of immune cells and their functions observed in individuals with PPS were different from those from healthy individuals or individuals with stable polio.

The data from the study show that PPS individuals have higher levels of antibodies and regulatory T cells circulating in their blood than healthy age-matched individuals, while stable polio individuals have variable levels of these immune components, which overlap with both the PPS and the healthy individuals.

The data from this study suggest that there is possible immune dysregulation occurring within polio survivors (both stable and PPS individuals). Importantly, however, there was a lack of sufficient data from stable polio subjects. This lack of sufficient data from stable survivors makes it difficult to make definitive conclusions regarding the role of regulatory T cells (and/or antibodies) as an easily available diagnostic marker for PPS. The cause for the increased levels of the immune components (antibodies and regulatory T cells) is currently unknown.

The observations from this study do, however, suggest that there is a problem with the immune responses in polio survivors, which could contribute to PPS. Whether immune components have a direct role in the initiation and progression of PPS or merely indicate the presence of a problem with the immune system in these individuals is unclear at this time.

Comparison of Manual Muscle Testing and Function pre and post triplanar control dynamic response AFOs in polio survivors

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Background: Patients, including polio survivors, who had been fitted with lower extremity orthoses made by Dynamic Bracing Solutions (DBS) had reported to their orthotists that they felt some of their muscles had gotten stronger after using the DBS brace(s). We decided to conduct a small pilot study to investigate whether there was evidence that muscle strength changed after bracing.

A pilot study was done in 2006 with the first five polio survivors in Colorado who were each fitted with a DBS ankle foot orthosis (AFO). The subjects ranged in age from 59 to 80 years of age, three were women and two were men. The mean time since their original polio diagnosis was 60 years. Each subject had at least one manual muscle test (MMT) done 3 months to 4 ¾ years prior to being fitted with the brace; repeat MMT was done on the braced leg three months to twenty months by the same medical team that had done the original manual muscle testing. Each of the five subjects had improvement in strength in at least two of the seven major muscle actions (ankle dorsiflexion, ankle plantarflexion, knee extension, knee flexion, hip flexion, hip abduction, and hip extension) after wearing the DBS brace; one had improved strength in three muscle actions; one had improvement in five muscle actions and one had improvement in six. One of the subjects did also have decreased muscle strength in two of the major muscle actions.

In 2008-2009, a second study was done on five additional polio survivors who had been fit with DBS orthoses – three had a single AFO, one had bilateral AFOs and one had a KAFO. The subjects ranged in age from 57 to 68 years old and included four women and one man. These subjects had MMT done four to seven months prior to being fitted with the DBS orthoses and then repeated three to nineteen months after receiving the brace(s) by the same physical therapist. The results of this study showed improved muscle strength in only 0-2 of the seven major muscle actions in the ***braced*** leg, <u>but</u> showed improvement in muscle strength in 2-6 major muscle actions in each of the subjects who had a unilateral brace in the ***unbraced*** leg (four of these unbraced legs also had some post-polio weakness and/or deformity)

Five of the six subjects had enough weakness of their quadriceps and gastrocnemius that they would have been normally been prescribed a locked knee KAFO. But each of these people was successfully fit with a DBS AFO.

In the course of interviewing and examining each of the 10 subjects all reported improved function in their personal, professional, and recreational activities. Two had significant decrease in pain in their ankles while wearing the DBS orthoses; one had elimination of long standing back pain.

Summary: Data from this small study suggests that improvement of muscle strength may be possible in some polio-affected muscles after use of orthoses that are constructed utilizing triplanar control and dynamic response. It appears that muscle strength in the unbraced leg may also be improved, possibly as a result of decrease in overuse of that extremity.

Discussion: Further research is needed to determine if bracing results in decreased, increased, or no change in muscle strength (no studies have really investigated this, although the common concerns has been that wearing a brace promotes muscle atrophy and disuse of some muscles; different methodologies of bracing also need to be compared in this regard. In addition, objective research is needed to compare gait efficiency, energy expenditures, and quality of life with different types of orthoses. This would allow “evidence based” decision making when prescribing an orthosis.

Bracing: What’s New? Is Old Better?

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What’s New in Orthotics?

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Introduction: “New” can, and is, many things. “New” can be technology, methodology, or a combination of both. New can be in the “eye of the beholder” or universally accepted as something different. My presentation will attempt to touch briefly on some of these issues.

Materials: Thermoplastics have now been used routinely for forty plus years. Traditional double and single upright systems are still provided. Traditional designs often incorporate thermoplastics and even laminates into “hybrid” systems. Today, titanium joints and uprights along with carbon graphite technology, represent the routine materials of the future. Medical grade silicones will augment comfort for limbs with very little protective padding.

Stance Control KAFO’s: This type of orthotic joint locks for stance phase and unlocks for swing phase. There are a wide variety of designs and manufacturers that are involved in this technology. A good resource to begin research is the American Academy of Orthotists and Prosthetists web site: www.OandP.org. Another good web site is: www.OandP.com where you can link to some of the manufactures.

Microprocessor controlled joints: Now routinely used in prosthetics, it is, in my opinion, only a matter of time for the crossover to the orthotic field to occur. This crossover should make the concept of stance control more consistently reliable.

Methodologies: I feel at least six main methodologies are emerging.

First, computer aided design and manufacturing is becoming a more routine part of the orthotic and prosthetic industry. Digital imaging has been used prosthetically for some time and is now becoming routine in scanning for cranial helmets in the treatment of plagiocephaly. Again, I think it only a matter of time until the technology is refined enough that it can be applied to lower extremity orthotics. This technology can also store digital shapes of limbs or spine and compared to future scans. Cast molds can also be documented and stored. A replacement mold from one of these scans can be a matter of a few clicks from the computer. Modifications can also be made within the computer.

Secondly, a renewed emphasis on the full weight bearing stance phase control will need to become routine. Outcomes for amputees did not improve to what they are today, until the stance phase control was addressed. Old principles, such as three point pressure systems and ground reaction mechanics, will be advanced to meet the complex demands of the stance phase. Orthoses will be expected to hold a planned Triplanar alignment even when subjected to full loading with a patient’s full weight in motion. The triplanar control in full weight-bearing can and will be documented by X-rays and compared.

Thirdly, bracing systems will be expected to provide the orthotic patient with a true dynamic response (energy return with a “push off”) just like artificial limbs do today for prosthetic patients.

Fourthly, the concept of designing a unique comprehensive walking solution for each individual will become the treatment model. The development of an elaborate walking solution from A-Z will then dictate the development of each treatment component including the pre-training program, the orthosis itself, and the post-training programs. Each walking solution will consider a very comprehensive set of details. To create a walking solution one must recognize the smallest details that affect the efficiency of gait (the study of Pathomechanics). A greater understanding will be required to not only recognize, but also solve, each and every one of the finite details at every aspect of the gait cycle. Each person will have a unique puzzle and a different set of issues to consider in the solution development. For instance, the skeleton is the most important structure in human locomotion. It is held in an anatomic position throughout the gait cycle by a combination of muscles, tendons, and ligaments. Any compromise to any of these structural components, will alter the skeletal alignment over time. As alignment is compromised, balance, stability, and efficiency will be affected. Unless a multitude of corrective Triplanar forces are applied to counter these deficits, they will continue to progress. The longer these issues go unchecked, the faster the deficits will accelerate and compromise efficiency even further. Increasing deformities, stresses, pain issues, the eroding of joint surfaces, etc. will all lead to a decrease in balance, stability and efficiency.

The fifth, is a concept of Remodeling deformities with more advanced bracing methods. Many fixed deformities normally require surgical procedures to correct. Remodeling techniques and new bracing designs will improve the alignment while walking. Corrective techniques have been utilized in non-weight-bearing applications for a decade or two. For many people who may want to prevent surgery or due to medical reasons that will not be offered surgery, the Remodeling methods will become a viable solution.

Finally, quantifiable outcomes will drive the development of evidence-based care and objective parameters will be better defined and measured. The body of science around lower limb orthotics will expand in the near future. Greater understanding and research will define and build the science needed to improve quality of life in a multitude of ways. Some preliminary studies are showing new bracing methods are offering benefits such as a reversal of disuse atrophy, reduction of pain, reduced incidence of falls, improved efficiency, reduced fatigue, reduction in the use of assistive devices, regained function and improved quality of life.

We at DynamicBracingSolutions™ are using some old principles in new and more complex applications. We are applying new bracing concepts to reduce fatigue and improve efficiency. We are taking advantage of carbon/graphite technology by combining it with new methodologies and applying both to improved patient care. A wealth of information is available on our web site: www.DynamicBracingSolutions.net. On the web site a plethora of topics is covered under "New Bracing Concepts". These topics include balance and security, Triplanar control and alignment, remodeling, and dynamic response. For more information on the complexities of Assessment (the crucial aspect of solution development), please review "Assessment for Polio Bracing is part of an Individualized Walking Solution," in this publication.

Is Older Better?

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True principles/laws always dictate the type of outcomes in which we are all subject. Many times we think that there are simple solutions to everyday challenges that come our way. Meeting these seemingly simple but complex demands become evermore challenging when it comes to providing support/stability to the ambulatory needs of the polio patient.

In the field of orthotics (bracing) technological advances allow us to use newer materials and designs vs. the standard methods and techniques used previously. However, the goals are basically the same and that is to provide assistance to compensate for the discrepancies that have developed from the results and effects the polio virus has left. The development of newer materials allows us to go from biological to technological areas. From animal/mineral (leather and metal) to thermo mold and themo setting plactics (polymers/carbon fibers/acrylic resins).

From the patient perspective, why change? “If it works, I’ll use it.”, “Don’t change it.” Even if the conventional orthosis (brace) is working, is it doing all it can or providing the best support/stability that is available? Regardless of the material or design, it has to provide for the needs of the patient. Example, provides free motion, assisted motion, restricted motion, stopped motion, and or restrained motion. Patients dealing with disabilities are subject to external forces applied upon them. In this day and age, science has provided us with much greater knowledge of these external forces and how these forces affect the ability for functional ambulation. These forces affect the quality of stability and alignment in the areas of toes, mid-foot, hind-foot, ankle, knee, hip, pelvis, low back, trunk, head, neck and the upper extremities.

There are some unique challenges in working with patients who have had polio with its paralyzing effects and now have issues dealing with post polio syndrome. Paralytic motor dysfunction along with sensory input (proprioception) is at times very difficult to work with. This sensory input can at times facilitate and also complicate orthotic management. Both hypersensitive from tissue that has experienced high demands of pressure and joints that have experienced years of overuse syndromes together create very challenging opportunities in orthotic management.

Enhanced knowledge of kinesiology (study of muscles and muscular movement) allows practitioners to take advantage of advances in materials and components. It is essential for the clinician of today to have an acute awareness of the pathology (in this case polio) to be able to answer the questions of: why, what, where and how. Why is the patient here? What instability does the patient have and what devices are being used?

Where are the deformities and where does the path-o-mechanical pathways (pathway of mechanical force) go? How is the body compensating for the loss of normal function? How are current devices being used help in these compensations?

The goal of orthotic management is to take advantage of these ground reaction forces and distribute these forces in orthotic designs that allows the patient to tolerate them within acceptable limits. Proprioception will determine what these limits are and how effective they will be in supporting and providing stability. Patients will always vary in their clinical presentations but usually fall into classifications concerning the foot, ankle, knee, hip and/or a combination of all including spinal and upper extremity involvement. Protection of non-stable joints is essential in order to prevent further path-o-mechanical forces that lead to additional deformities. If at all possible, joint motion needs to be preserved in order to enhance a direction towards a more normal gait pattern. Patients who present with the use of orthotic design and componentry of yesteryear, need to be evaluated as to the effectiveness of design, componentry, durability, adjustability, and bio-mechanical appropriateness. With or without orthotic intervention, the body has a wonderful way of compensating. With this compensation, comes deviations in gait patterns that can lead to further complications in the future. Ground reaction forces in different planes will challenge joints, muscles, ligaments and also orthotic componentry. Orthotic design must be able to specifically resist and direct these forces in a way that will be an advantage and tolerable to the patient. Older orthotic designs and devices that meet these demands will usually continue to be used.

The use of older orthtoics devices usually means, “Status Quo”. However, as physicians, practitioners, therapists have learned, “Status Ouo isn’t always the best route to take as patients age and the demands of ambulation increase. The use of newer devices usually means changes in bio-mechanical forces that will create new forces on the lower extremities. However with new technology and materials, the new forces, unlike the limited pressure areas of the past, will be distributed over broader areas that will be much more tolerable. Older devices usually means heavier with more energy consumption while newer lighter designs reduce energy consumption which is extremely important for continued stability, ambulation and keeping independence.

Finally, change comes much more easily when information about the change is provided. Discussion with education leads to a better informed patient. A well informed patient may be more willing to accept and try change. When the patient makes the decision to try something new, there is a higher level of acceptance and satisfaction with a better understanding of the whys, whats, wheres, and hows regarding newer orthotic design.

Is older better? In my opinion , with over 50 years of experience on the patient side of the exam table and 30 plus years of experience on the practitioner side of the exam table, I would answer: sometimes Yes, but usually No!

Exercise and Activity: How Much and What?
Let's get Practical

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I work at a Rehabilitation Center for polio and accident victims in Denmark. The Center is owned and run by a patient organization called: The Danish association of Polio and Accident Victims. All staff members are employed by the organization, but the counties in Denmark pay for the treatment, so all assessments and treatments are free of charge for the patients.

878 polio survivors were treated at our clinic in 2008. Around 300 polio survivors exercise on a regular basis in PTU once or twice a week in our training center or in the warm water pool. 10,5% of the polio survivors are immigrants. Around 50 polio survivors are annually referred to the center for the first time. Most of them are elderly Danes who have managed to live without our help until now, but we also get a lot of immigrants from third world countries who have polio. They are often much younger and have a lot of social and language problems on top of the polio difficulties.

We have 7 wheel chair accessible apartments where polio survivors from other parts of the country can stay while they attend a 1 or 3 week program at the center.

The center has a multidisciplinary team to take care of the polio survivor comprising: Doctor, physical therapists, technical aids therapists, social workers, psychologists, nurse assistants, dietician and a private orthotist, who is coming once a week. It is necessary to have a doctor's referral to our clinic. Before coming to the clinic the polio survivor is asked to fulfill a questionnaire about his or her social conditions (work situation / housing), the acute and stable phase and the actual problems that have made the patient come to the clinic. The doctor makes an examination of the patient, and she considers if there could be other differential diagnoses, which could cause the symptoms of the patient. She can then refer the patient to different professionals at the clinic or to additional tests at a hospital. Almost all the patients are referred to physiotherapy.

When all the relevant professionals have assessed the polio survivor, a conference is held where all assessments from the multidisciplinary team are presented and we agree on which recommendations should be given to the patient. It is important that we all work in the same direction and of course the plan is made in cooperation with the polio survivor. When there are complicated matters, the patient participates in the conference.

Some polio survivors need changes in there home or at the place of work. Our technical aids therapist can visit the polio survivors home together with the therapist from the county in order to find the best adjustments. Some polio survivors need to save their energy, so they need technical aids, bandages or help with housecleaning. If the patient has a seating problem we can measure the pressure of the buttocks in the seat, which makes it easier to find the right cushion for the wheel chair.

We also have a polio education program where polio survivors and their relatives can learn about polio issues, exercising principles, technical aids and psychological reactions to the need of changing lifestyle as polio problems arise. I could tell a lot about what all the professionals do but I will focus on the physiotherapy and especially how we deal with exercising according to the title of this session.

The physiotherapist uses a check scheme to make a thorough anamnesis and examination of the patient. We use this to be sure that we get all necessary information about the patient and his or her condition before we make a treatment plan.

If the main problem is pain we consider the cause of the pain. Is it overuse of the body structures or is it a more diffuse pain in the polio muscles. Depending on which kind of pain the patient has, we use a variety of pain treatments: Exercise, acupuncture, laser therapy, medication, massage, relaxation, energy conservation, bandages, aids, etc.

If the patient experiences a decrease in strength we always make a manual muscle test. We know that the test does not give us the exact truth about the polio affection, but it gives us a good impression of how much polio affection there is. You can see on the slide that the manual muscle test only detects rather big decreases in strength, but we are therefore aware that there can be polio in a muscle, even if it seems strong in the test.

Grade

0	No muscle contraction	0%
1	Palpable contraction	< 5%
2	Gravity eliminated	5 – 10 %
3	Against gravity	10 –20 %
4	Moderate / good	40 %
5	Maximum resistance	> 60 %

We use the manual muscle test as a guideline for how the patient should exercise or which kind of bandages could be useful. During testing we can also see and feel if there are fasciculations during the test, which tell us that the muscle can be overused. Sometimes we can compare a recent test with a test taken some years earlier and in that way we can follow the development of the decrease in muscle strength. I should maybe mention that we do not take EMG measurements regularly in Denmark. We have very good journals of the patients polio history from their initial hospitalization and we find that the muscle test is enough in most cases.

To be able to tell if the treatment makes a difference we also use other tests. Not for everybody, but when it is relevant. I will mention these tests:

- 6 min walk test which is the distance walked in 6 minutes as fast as possible.
- Time used to walk 10 meters,
- Walking distance outdoor where the patient walk until he or she needs a break. We use this when applying for car or a parking sign.
- We also have balance and fitness tests.
- Timed Stands Test which measures the time necessary for getting in and out of a chair 10 times without using the arms.

After hearing the polio survivor’s story and performing the tests we make an evaluation to decide whether the problems are caused by disuse, overuse or maybe something else.

As in the States Denmark also has a rising number of lifestyle related diseases. The Health Department in Denmark recommends that everybody should do at least moderate exercising for 30 minutes each day. The polio population is in high risk of getting life style related diseases, because they often have a lower activity level than the rest of the population. The well-known life-style related diseases are: Hypertension, diabetes, osteoporosis, cardio-vascular diseases and depression. So even though a person has polio, he has to maintain a certain level of activity if possible and he has to keep his weight down in order to avoid further complications to his condition. The two main ways of handling this is healthy diet and exercising.

So what are the exercising recommendations for polio survivors in Denmark?

When we examine the patient we consider what status the muscles have. Is the strength stable or unstable? As you can see our recommendations of exercising the patients depends on the strength level and if the muscles are stable or not. By stable I mean, that there have not been more decrease in strength than could be explained by age. The last line in the slide represent the muscles that are so overused through daily activities, that they should not exercise more. But only very few patients cannot exercise at all. Most patients can benefit from exercising even in a very light way

Exercise and Activity: How Much and What? Let's Get Practical

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Demystifying the Equipment of Assisted Breathing

Brenda Butka, MD, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Kristy McClellan, RT, Vanderbilt Stallworth Rehabilitation Hospital, Nashville, Tennessee

Betsy Thomason, BA, RRT, Millennium Respiratory Services, Whippany, New Jersey

Accessible Housing for Aging Polio Survivors: Problems and Solutions

Maria Pellerin Barcus, Housing Partners
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SESSION S4

Polio: A Look Back at the Public Health Crusade that Mobilized a Nation

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The battle against polio mobilized an entire nation against the mid-20th Century's most feared disease. It came at the height of public confidence in medical research, and it involved tens of millions of ordinary Americans who donated their time and their money to a voluntary effort that produced two successful polio vaccines following the largest public health experiment in world history. Led by the National Foundation for Infantile Paralysis, the polio crusade revolutionized both fundraising and medical research in the United States, as well as the way in which the federal government tested and licensed new drugs and vaccines before allowing them on the market.

In the process, the National Foundation created an enormous research and rehabilitation structure, some of which is still in place today. I call this an "American Story" – although its reach is global – because the largest polio epidemics occurred in the United States, and the battle to contain the disease was planned and carried out within our borders.

Note: A limited number of paperback copies of *Polio: An American Story* by David M. Oshinsky will be sold for $13.00 prior to the presentation, which will be held in Roosevelt Auditorium. Oshinsky, who won the Pulitzer Prize in History in 2006, will be available after the session to autograph copies of his book.