Medical Management of Post-Polio Syndrome

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As the number of polio survivors gradually decreases in the US, finding medical providers familiar with post-polio syndrome is becoming more difficult. An individual provider is not able to develop expertise when experience is limited to a few patients per year. This necessitates that the polio survivor become an “expert patient.”

The term “expert patient” originated in England and refers to patients who have the confidence, skills, information and knowledge to play a central role in the management of life with chronic diseases. This concept has become part of medical education in the United States. Medical students are trained to provide more patient education and rely on the patient as part of the medical treatment team to contribute to decision making regarding their care.

To be an effective “expert patient” it is important to keep expectations realistic. Do not expect a primary physician to know much about post-polio syndrome. Be able to provide concise, scientifically based information for your physician. The Post-Polio Health International website (www.post-polio.org) has information for medical providers that can provide basic medical information and serve as a resource for specific conditions. Do not bring stacks of unreferenced information from the internet to your provider!

Establishing a good relationship with your primary doctor is key to accessing the medical care you need for the symptoms related to aging with polio sequelae. Medical management of post-polio syndrome includes management of the primary symptoms, treatment of underlying or associated conditions and optimizing health and wellness. Individual treatment plans include a detailed medical history and exam to identify problems, potential problems or health risks and goals. Identifying associated medical, neurological, musculoskeletal and psychological conditions are part of the process. Evaluation may require consultation with a specialist such as a physiatrist, neurologist, orthopedic surgeon, pulmonologist or otolaryngologist. Interventions may include referral to a physical therapist, occupational therapist, speech language pathologist, orthotist or psychologist.

It is important for providers to recognize the unique physiologic aspects of residual paralysis due to polio. Polio survivors have a number of muscles that have lost some percentage of the normal innervation. These muscles cannot strengthen like normal muscles and lose proportionally more strength with aging. If polio occurred in childhood, bone and joint development were affected in the involved limbs. Muscle imbalances and joint deformities alter body mechanics and put increased stress on the musculoskeletal system, resulting in early degeneration. Body composition, or the ratio of muscle, fat and bone may be significantly altered and affect metabolism. Many of the symptoms of post-polio syndrome are like those of aging but accelerated and more complicated. Goals of treatment are to minimize symptoms of post-polio syndrome,
optimize body mechanics, protect weak muscles and joints, decrease physical demands on the body, treat associated conditions and optimize wellness.

The primary symptoms of post-polio syndrome are excessive fatigue, muscle and/or joint pain, new weakness, cold intolerance, and dysphagia or respiratory changes. Each of these symptoms may be exacerbated by other factors that should be addressed as part of the medical management.

Fatigue is a very non-specific symptom with many potential causes and contributing factors. Fatigue is exacerbated by poor sleep, deconditioning, obesity, poorly controlled chronic illness and depression in addition to the fatigue associated with overuse of weak muscles and post-polio syndrome. Managing fatigue involves optimizing body mechanics and cardiovascular health in addition to conserving energy.

Pacing activities with intermittent rest periods is key. This may require a change in lifestyle or work schedule. Sleep must be optimized by identifying and treating sleep apnea or hypoventilation at night, pain that interrupts sleep, or anxiety that may prevent sleep.

Muscle and joint pain associated with post-polio syndrome is often a result of overuse or excess stress on the body. Muscle pain commonly occurs in polio-affected muscles that have functional strength, putting them at risk of overuse. The pain may be associated with cramping, twitching or crawling sensation and is typically worse at the end of the day. Post-polio muscle pain is a warning sign of overuse and muscle tissue damage. Preventing the pain by modifying activity and stress on a muscle is an essential part of treatment. Using pain medication to simply mask symptoms may ultimately lead to further damage and loss of function.

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Joint pain may be due to degeneration and inflammation in the joint or stress on the connective tissue surrounding the joint. It may occur in a polio-affected limb where there is excess stress on a joint due to joint deformity, altered body mechanics, or poor protection due to weak muscles and ligaments or in a “strong limb” which has been subjected to years of overuse.

Treatment of joint and soft-tissue pain must include evaluation and modification of body mechanics. This may require weight loss, physical therapy, bracing, assistive devices or mobility aids. Treatment may also include modalities, medication, injections and, at times, surgical intervention.
New weakness in polio survivors may manifest in muscles known to be affected by polio or in muscles thought to be unaffected. Most likely the “unaffected” muscles had sub-clinical motor neuron loss at the time of the acute polio infection. Loss of motor units and degeneration of the axon sprouts developed when muscles were reinnervated results in the weakness associated with post-polio syndrome. Medication has not been shown to be effective in preventing loss of strength unless other factors such as low testosterone or neuromuscular transmission defects are also present.

Avoidance of overuse of “at risk” muscles and appropriate exercise to strengthen deconditioned muscles can delay loss of function. Identifying which muscles are weakening due to overuse and which have become deconditioned by changes in mobility requires very careful muscle testing and monitoring.

Cold intolerance, like fatigue, is a non-specific symptom common to polio survivors. Limbs with significant muscle atrophy related to polio have reduced blood flow and microcirculation due to minimal oxygen demand. Individual basal metabolic rate, related to amount and percentage of muscle tissue, is reduced in a polio survivor. Cold intolerance can be managed by improving cardiovascular circulation, insulating with layers of appropriate breathable clothing, and ensuring availability of environmental control and external heat sources.

Dysphagia and respiratory problems are related to a history of bulbar polio with residual weakness of upper airway, swallowing and respiratory muscles. A history of choking or coughing when eating or difficulty swallowing certain foods may warrant a swallowing evaluation and training in compensatory swallowing techniques.

Reduced respiratory function may be a result of upper airway obstruction (weakness of muscles in the throat) or poor ventilation due to chest wall or diaphragm muscle weakness. Pulmonary function tests and sleep studies can identify the etiology of symptoms and indicate appropriate interventions.

Optimizing wellness contributes to overall health and sense of well-being. A good relationship with a primary care provider is essential to monitoring health and managing chronic conditions. Good nutrition, restful sleep and regular exercise help maintain vitality. Preventing injury and illness and modifying lifestyle to minimize risks are key to preserving function. Psychosocial support lends security and purpose to life.

Although post-polio syndrome can be a complicated condition to live with, finding the needed medical management and living well is still possible.
In the villages of Masindi, Uganda, there are not enough wheelchairs for the adults and children who need them. Without access to wheelchairs, all individuals with mobility limitations must crawl along village dirt roads or be inappropriately and unsafely carried for mobility. Skin abrasions, fungal infections, and injuries from falls are common secondary health conditions witnessed as a result of this crawling and carrying.

Many individuals in need of wheelchairs are affected by polio. Although Uganda has had no reported polio outbreaks since October of 2010 because of vaccination programs, previously infected individuals continue to demonstrate permanent mobility limitations and the need for wheelchairs.

Despite the widespread need for wheelchairs, there are no social safety nets to assist adults or children in Uganda with securing one. And adults and children who need a wheelchair are too poor to purchase one. The average cost of a very basic wheelchair in Uganda is at least $163 dollars, while the average monthly income of Ugandans in the Masindi region is $83 dollars. Downstream effects of lack of wheelchair access include unemployment, poor education, and less supportive networks.

One simple solution to address the health and societal participation problems is supporting wheelchair access and delivery for adults and children with mobility limitations. But barriers, of course exist, including 1) demand for disability services surpasses supply, 2) absence of social assistance programs for individuals with disability, and 3) poverty.

For almost ten years, teams from the Medical University of South Carolina (MUSC) have tried to address these barriers by collecting five to seven used, manual wheelchairs and imported them into Masindi, Uganda during medical mission trips that occur in collaboration with OneWorld Health (OWH) (www.oneworldhealth.com). Using a quarterly, medical mission, mobile clinic model, OWH interprofessional healthcare teams practice across a variety of villages in Masindi, Uganda with the goal of improving health outcomes of the Ugandan people.

Noting the need for wheelchairs in Uganda during these mission trips, MUSC faculty and students have attempted to develop solutions. Although, these wheelchairs have definitely filled a void for adults and children with mobility impairments, four concerns consistently arise:

- Used, imported wheelchairs cannot meet the specific needs (e.g., wheelchair size, pressure relief cushions) of the individuals being served and may cause additional harm (e.g., pressure wounds, fall from a wheelchair that lacks a seat belt);
- Used wheelchairs imported from high resource countries, like the United States, do not address the challenging terrain of Uganda;
- Mission teams never have enough used, imported wheelchairs to serve all the adults and children needing wheelchairs; and
Importing used wheelchairs is not a sustainable method of providing wheelchair access, delivery, and repair to adults and children with disability.

Uganda needs an average of 4,464 wheelchairs per district in each of its 127 districts. District authorities estimate that there are approximately 500 wheelchairs within each district, of which 75% are imported. Wisely, the Ugandan government recognizes that these wheelchairs are too generic and not based on the user’s specific needs, posing health and safety concerns. These imported wheelchairs may also have a negative impact on in-country wheelchair production and delivery.

To address this wheelchair shortage issue, MUSC faculty and students have developed a project to build capacity towards sustainable access and delivery of RoughRider (RR) wheelchairs for adults and children with mobility limitations in Masindi, Uganda. The RoughRider wheelchair was specifically developed for use in low resource and rugged countries like Uganda. This wheelchair is easily assembled, comes in six sizes, has adjustable seating that allows for the fitting of individual postures, and utilizes bicycle tires that can be repaired or are available in Uganda.

In May of 2019, MUSC faculty and students carried out the first-ever wheelchair seating and mobility clinic in Masindi, Uganda at OWH’s Masindi Kitara Medical Center. Using the World Health Organization’s Wheelchair Service Training documentation (www.who.int/disabilities/technology/wheelchairpackage/wstpintermediate/en), four adults and two children were evaluated for and provided with individualized wheelchairs. The health condition of three of these six individuals was polio. In addition to delivering wheelchairs, MUSC faculty and students assessed wheelchair mobility operation, provided individualized mobility training, and discussed basic wheelchair cleaning and repair.

In May of 2020, MUSC faculty and students will return to Masindi, Uganda to carry out a larger wheelchair seating and mobility clinic with a goal of delivering 100 RoughRider wheelchairs. Importantly, they will also begin educating Ugandans in wheelchair assembly and Ugandan physical and occupation therapists in wheelchair assessment. Creating sustainable wheelchair access and delivery in Masindi, Uganda over the next five years is the ultimate goal.

For more information on this project, contact Cindy Dodds, PT, PhD at doddscb@musc.edu or watch this video: https://vimeo.com/user101992039/review/354722413/d61d55a641

If interested in donating, please visit on fundraising link through OneWorld Health: https://bos.etapestry.com/fundraiser/OneWorldHealth/wheelchairproject/

References
Details for 3rd European Conference on Post-Polio Syndrome Announced

Following the successful 2014 international post-polio conference in Amsterdam, organizers have announced that the 3rd European Conference on Post-Polio Syndrome: “Improving care for Polio survivors” will be held in Vitoria-Gasteiz, Spain from June 10-12, 2020. The conference is being organized by Rotary Vitoria, the European Polio Union, Amsterdam University Medical Centers, the Netherlands and Polio Denmark.

This three-day international conference in the heart of Spain’s Basque Country aims to improve care for polio survivors who are confronted with post-polio syndrome, both throughout Europe and worldwide. It will bring together an international audience of polio survivors, health care professionals from multiple disciplines, and researchers to exchange knowledge and experiences.

There will be sessions aimed directly at polio survivors and health care professionals, but also sessions for all attendees, to discuss the needs of polio survivors, the available care options, future research priorities and to explore opportunities for collaborations. The conference will also hold interactive workshops.

The organizers list the main topics as follows:

- Diagnosis and Therapy
- Symptom Management
- Multidisciplinary Rehabilitation
- Orthotic Devices
- Best Practices
- Latest Research Results

The conference sessions will be conducted in both English and Spanish with simultaneous translation. Translation will also be available in French and German in one track.

Registration is currently open.

For further details about the conference:
www.postpoliocongress.com
Short Documentary Examining Medical Assistance in Dying Features Audrey King

The Canadian Association for Community Living (CACL) recently posted a short documentary, “Flourishing: Audrey King,” that touches on issues regarding medical assistance in dying and its potential impact upon individuals with disabilities.

The video is part of the CACL’s “Promoting Human Flourishing in the Context of Medical Assistance in Dying” project. The project was designed in response to Canada’s June 2016 passing of the Medical Assistance in Dying (MAiD) legislation, particularly worries about oversight and regulations, and what choices might be made when MAiD is mixed with societal stereotypes.

Audrey J. King, MA, is a Toronto native and a dedicated and effective advocate. King is a ventilator user due to childhood polio and her efforts over the years have been a quest for independence for herself and for other ventilator users.

In 2017, she was awarded the Margaret Pfrommer Endowed Memorial Lecture in Home-Based Mechanical Ventilation at CHEST 2017 in Toronto, Canada. The annual award is given to a clinician or ventilator-assisted professional/advocate who has advanced the areas of mechanical ventilation and fostered partnerships between physicians and patients. Video of that lecture is available at www.ventnews.org/ventilator-assisted-living-32-5.

PHI is now on Instagram

Post-Polio Health International has created a new account on Instagram. You can follow us at @postpoliohealth. The account will post a mix of historical tidbits, highlights from our archives, current happenings in the post-polio community, and updates on what PHI is up to.

“We are always looking to reach new audiences. Instagram will not only allow us to connect with those unfamiliar with our organization, it will allow us to communicate with our many members in a new, visually pleasing style,” explains PHI Executive Director Brian Tiburzi.

If you don’t already have an Instagram account, it’s easy to sign up for one. Simply download the app in the Apple App Store or Google Play Store, or sign up at www.instagram.com.
**PHI:** I have always been a fairly active person. I have a good circle of friends, and we like to meet up for various outings—nothing too strenuous, just going to plays or museums, meeting up for lunch, going shopping, etc. Like many people that had polio and are getting older, I can’t quite do as much as I used to. Certain activities just tire me out. There are times (not all the time) when I’d rather just stay home and read or watch TV. I’m afraid, though, that if I start to opt out of our regular outings, my friends will start to just not ask me to things in the future assuming I don’t have the energy for it. I don’t want to feel excluded. How do I balance this with my need to slow down a bit?

**Response from Stephanie T. Machell, PsyD:**

Regardless of age, this is a common dilemma for people with disabilities. Temporarily able-bodied people rarely understand the issues involved in living with a disability, including the need to pace oneself and conserve energy, or the way a “bad” day might mean a sudden change of plans. The more “invisible” someone’s disability, or the more that person’s condition seems similar to something familiar (such as normal aging) the more puzzling these needs may seem. And because most people’s mental model for disability is based on what is familiar to them (e.g., acute conditions), the lack of improvement and/or cure causes further confusion.

As you fear, well-meaning friends may assume it’s kinder not to invite you. Or they may feel hurt at what they perceive as rejection and stop asking to avoid more rejection. No matter the reasons, the result is increased social isolation and loneliness.

What can you do? First spend some time thinking about what kind of social life would suit you best. Being clear with yourself will help you be clear with your friends. For example, if certain activities tire you out, maybe you’d prefer to opt out of them altogether and conserve your energy for the ones that don’t. Maybe you’d rather be asked on all outings, reserving the right to say yes or no depending on how you’re feeling. Or maybe you have thoughts about some new activities or ways of getting together that might be less fatiguing.

It can be awkward to discuss something as personal as your disability, especially if these are “activity” friends rather than close ones. Often people believe the only way they can justify themselves is to provide more details than they may be comfortable sharing.

Think about how much (or little) you want them to know beforehand. It can help to develop an “elevator speech,” i.e., something brief and to the point. Consider how you’ll respond if your friends ask questions.

Now it’s time to talk with your friends. If you’re closer to one or more than the others, you could start with them. Be clear about what you want and need, how much you enjoy their company, and how important it is to you that this continue. You might discover you’re not the only one who feels the way you do. Good luck!

**Dr. Stephanie T. Machell** is a psychologist in independent practice in the Greater Boston (MA) area. She specializes in working with those affected by polio and other physical disabilities. Her father was a polio survivor.
Response from Rhoda Olkin, PhD:
I’m going to address how to make decisions about slowing down. Most of us have to do this as we age with polio. Using a mobility device is one option for energy conservation, but reading over questions from the past, it seems that many people feel it is an admission of defeat to use a scooter or wheelchair. But mobility devices are not the only option.

Let’s do a thought exercise to work through how energy affects us. Suppose you had 258 pennies, each of which represents some amount of energy. Every action you do costs some number of pennies. As you go through the day the number of pennies dwindles. If you go over your allotment of 258 pennies you will start the next day with fewer pennies and need to do more things to replenish your supply. In an ideal world you would spend about 200 pennies a day, always leaving some in reserve for unavoidable events, and never going over your limit.

But the problem is this: you don’t know how many pennies you have each day, and the number varies from day to day. The only way to really know how many pennies you have is to go over the limit a bit several times, and computing what the outer limits are. Furthermore, each decision to spend a penny is a decision not to spend it on something else. So slowing down is all about making choices of what we want to spend our pennies on, and what we don’t feel is worth the penny.

Reserving a large portion of your pennies for socialization is one of the most important things you can do, as shown by studies on aging well. You don’t have to be a social butterfly, saying yes to everything. But I would advise doing at least one to two social activities a week. This might mean cutting down expenditure of pennies elsewhere. The times you spend reading and watching TV are also important—you are lucky in that you like time by yourself. Those times may be nurturing as well.

Using a mobility device is one option for energy conservation, but reading over questions from the past, it seems that many people feel it is an admission of defeat to use a scooter or wheelchair.

Could you make a list of everything you do in one week? Now cross off at least five things. Or make trades—going to a play this week means not going out to dinner until next week. But beware of all-or-nothing thinking. Turning down a social outing or two does not mean friends will drop you.

Practice this line: “I have X on Friday so I believe I’ll be too fatigued for Y on this Saturday but would love to do Z with you next Saturday.” Friends should understand.

Dr. Rhoda Olkin is a Distinguished Professor of Clinical Psychology at the California School of Professional Psychology in San Francisco, as well as the Executive Director of the Institute on Disability and Health Psychology. She is a polio survivor and single mother of two grown children.
Question: My wife contracted polio at the age of eight. She experienced some paralysis on her right side, but with physical therapy and some bone grafts to strengthen her right leg, she made a good recovery. She is now 75 and has been experiencing some post-polio symptoms, notably general weakness, instability and some falls. She has had some difficulty swallowing her throughout her life but generally has functioned well until lately.

Recently, she was hospitalized for pulmonary edema (probably due to worsening heart disease and atrial fibrillation). During her hospitalization, she was intubated for a relatively short period of time to assist in her oxygen while the fluid was drained from her lungs. After extubation, swallow studies indicated a worsening of her swallowing issues. We think this was likely due to the intubation trauma. She was sent home on a Level 3 Dysphagia diet, which we are dealing with, but her risk of aspiration into her lungs has definitely increased.

This is not really a question, but a cautionary tale that perhaps should be shared for post-polio sufferers like herself whose swallowing ability is impaired and which can be worsened if they are subjected to intubation for general anesthesia during operations, pneumonia, or other such hospitalizations. The downside of too much throat trauma and swallowing disfunction could result in a permanent feeding tube and significantly reduced quality of life. Fortunately, we are not there yet but may be facing some serious decisions in the future if her health deteriorates.

Dr. Maynard: Thank you for sharing your wife’s story. I agree with your assertion that polio survivors with even mild swallowing problems are more at risk of significant and problematic dysphagia after intubation. Such a relationship would unfortunately be very difficult to ‘prove’ scientifically to the mainstream US medical community because of the many potentially confounding variables and the subsequent large number of subjects required. Ideally, a patient in your wife’s acute condition of needing short-term respiratory support could have been successfully managed with non-invasive ventilation techniques, that is, without intubation. There are other complications of intubation also, such as voice problems and infections that can also be avoided with non-invasive techniques.

I am going to ask Dr. John Bach, who is an expert on this subject and has published extensively in PHI’s Ventilator-Assisted Living, to recommend professional articles that a post-polio patient similar to your wife could potentially share with their physicians when they are facing similar cardio-pulmonary crises requiring external ventilatory support via intubation.
**Dr. Bach:** I agree it is common for dysphagia to be exacerbated by intubation, but it usually clears up after a few months. A modified barium swallow test or fiberoptic evaluation of swallowing (FEES) test can definitely show aspiration on swallowing or not. When aspiration is severe, the O2 saturation goes below 95% during meals, and the risk of pneumonia is great.

The other concern your wife’s story raises is whether a post-polio patient’s pulmonary edema has developed because they are hypoventilating during sleep. Carbon dioxide retention during sleep can lead to pulmonary edema, with or without other heart disease. If there is any history of morning headache, daytime drowsiness and/or fatigue, sleep study evaluations are indicated.

The following three articles could be given to a physician of a post-polio patient who has developed severe enough pulmonary edema to consider intubation treatment. They describe results of treatment for pulmonary edema with non-invasive ventilation.


http://www.rcjournal.com/contents/02.09/02.09.0186.pdf


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Vol. 35, No. 4, Fall 2019

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