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PHI's 9th Research Award: Final Report

Cough Assist: User Education Needs, Health Service Utilization and Outcomes

Louise Rose, RN, BN, MN, PhD, King's College London and
Mika Nonoyama, RRT, PhD, University of Ontario Institute of Technology

BACKGROUND

Individuals that require ventilator support in the home due to neuromuscular disorders experience frequent chest infections. When severe, this results in emergency department visits and, in some cases, hospital admission.

Cough assist devices that help clear respiratory secretions may help prevent chest infections or lessen their severity. This may help reduce use of healthcare services and associated costs, as well as reducing symptom burden and improving quality of life.

In April 2014, the Ministry of Health and Long-term Care in the province of Ontario, Canada, set up a publicly funded program to provide free-of-charge cough assist devices and associated equipment based on a home ventilation specialist prescription.

PROJECT AIM

Our project was designed to understand the following:

- ◆ What education and support is required for cough assist users and their families when newly started and for ongoing use of a cough assist device.
- ◆ The impact on publicly funded healthcare services and costs, health-related quality of life and symptom burden.

METHODS

We conducted this study in three parts.

In Part 1, we conducted interviews with new (<6 months) and established (6–48 months) cough assist users and family caregivers. We also asked them to rate their confidence using cough assist on a 1 (not confident) to 10 (very confident) rating scale.

In Part 2, we prospectively recruited participants who received a cough assist device through the publicly funded scheme. We then used the Ontario health administrative databases to understand the publicly funded healthcare service use and costs of these participants in the 12 months before using cough assist and in the first 12 months of use.

In Part 3, we assessed health-related quality of life and self-reported breathlessness at three, six and nine months. We also collected a broader understanding of both public and private healthcare costs using participant-reported data as opposed to health administrative databases.

FINDINGS

Part 1: We conducted 28 interviews, including 14 new and 14 established cough assist users and caregivers. Both new and established users were highly confident in use of cough assist, with average scores

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Louise Rose, RN, BN, MN, PhD

of 8.8 and 8.3 respectively. Overall, interview participants were satisfied with their initial education which generally comprised a 1–2 hour one-on-one session at home or in clinic with device demonstration and hands-on practice. They viewed hands-on practice and teaching of caregivers as more beneficial than written materials.

Participants reported ongoing support for cough assist use was variable. Most indicated a lack of specific follow-up resulting in uncertainty if they were using cough assist correctly, or if it was effective.

Things that made interview participants more likely to use cough assist were that it was easy use, the initial training, support from formal/informal caregivers, and that they experienced symptom relief. Barriers to use were inadequate education on why cough assist was needed, technique and benefit, lack of follow-up, and inadequate knowledge of cough assist by community/non-specialist providers.

Part 2: We recruited 106 adults and children using a cough assist device. We found no difference in emergency

department visit or hospital admission rates in the 12 months before and 12 months after receiving a cough assist device. However fewer days were spent in hospital ($P=0.03$). We also found the number of physician specialist visits decreased from seven to four visits on average ($P<0.0001$). Conversely, the use of homecare nursing and homemaking/personal support visits increased.

We found that the difference in healthcare costs before and after commencing cough assist differed.

“The most important predictor of costs after cough assist approval was the healthcare costs in the 12 months before receiving a device.”

For most (59%) participants these were lower, for 13% they were not different, and for 27% they were higher. The most important predictor of costs after cough assist approval was the healthcare costs in the 12 months before receiving a device. At 12 months, 23 (22%) participants had died, with the risk of death highest for those using more medical devices in the home.

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info@post-polio.org

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Post-Polio Health International's mission is to collect, preserve and make available research and knowledge to promote the well-being and independence of polio survivors, home ventilator users, their caregivers and families, and to support the health professionals who treat them.

How to contact PHI

50 Crestwood Executive Center #440
Saint Louis, MO 63126 USA
Phone: 314-534-0475
Fax: 314-534-5070
info@post-polio.org
www.post-polio.org
www.polioplace.org

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Part 3: We recruited 108 cough assist users, with most common diagnoses being ALS (40%) and muscular, myopathic and myotonic dystrophies (25%). Daily cough assist device use was 51% of study days on average. We found no change in health-related quality of life overall over the nine-month study duration. The average self-reported breathlessness worsened from a score of 2.1 at baseline to 3.1 at nine months. The average monthly cost of publicly or privately funded healthcare

“Provision of publicly funded cough assist devices did not change the number of emergency department visits or hospital admissions but did reduce the number of days in hospital and specialist doctor visits.”

was \$1,195 CAD, although costs were substantially higher in some participants. Higher costs were associated with an ALS diagnosis, requiring mechanical ventilation, being non-ambulatory and using the cough assist device on more study days.

OVERALL CONCLUSIONS

Part 1: The current Ontario model of education for the use of cough assist in the home on initiation meets cough assist user and family caregiver needs. Improvements to follow-up education are needed to sustain device benefit and maintain confidence in technique.

Part 2: Provision of publicly funded cough assist devices did not change the number of emergency department visits or hospital admissions but did reduce the number of days in hospital and specialist doctor visits. This resulted in a shift of healthcare utilization and costs from the acute care to community sector. The risk of death was highest in individuals requiring multiple medical technologies in the home that included cough assist.

Part 3: We found no change in health-related quality of life in the first nine months of using a cough assist device but a small worsening in self-perceived breathlessness. Similar to our previous work in home ventilated patients, costs were highest in participants with the greatest disease/symptom severity, including those with ALS, requiring ventilation, non-ambulatory, and also those using cough assist on more study days. ■



Mika Nonoyama, RRT, PhD

PUBLICATIONS TO DATE

Dale CM, McKim D, Amin R, Carbone S, Fisher T, Goldstein R, Katz S, Gershon A, Leasa D, Nonoyama M, Pizzutti R, Tandon A, Rose L. Education Experiences of Adult Subjects and Caregivers for Mechanical Insufflation-Exsufflation at Home. *Respir Care*. 2020 Dec;65(12):1889-1896.

Rose L, Fisher T, Pizzuti R, Amin R, Croxford R, Dale CM, Goldstein R, Katz S, Leasa D, McKim D, Nonoyama M, Tandon A, Gershon A. Health Care Use, Costs, and Survival Trajectory of Home Mechanical Insufflation-Exsufflation: Health Database Case Control Study. *Respir Care*. 2021 Oct 20;respca.09263. doi: 10.4187/respca.09263.

COVID and Polio Survivors Two Years into the Pandemic



Marny K. Eulberg, MD

It has now been over two years since COVID-19 was first identified and the world began to deal with it. We thought that, certainly in 2020, with our years of learning and all our technology, we'd be able to conquer and vanquish this tiny little virus. We have made strides with the development of multiple vaccines, treatments, learning more and more about how the disease passes from one person to another, and learning how to better monitor and treat those who become infected. Yet here we are, with waves of infection occurring with one variant after another and the disease still very much in our midst and on our minds.

Information specific to polio survivors was published and circulated by many polio-related organizations. But as recently as December 2021, I still was receiving occasional calls from polio survivors questioning whether they should get the vaccine. In my personal interactions with polio survivors, it appears that the majority have taken the steps to be fully vaccinated. I think this is because polio survivors are fully aware of what damage a tiny virus can do to one's body, and they have wished that the polio vaccine had been available prior to their contracting polio.

A theory was proposed that, perhaps, individuals who had contracted or been immunized for other viral infections (such as polio) might also have some immunity to COVID. In the real world, we do know that some polio survivors have indeed been infected with COVID and some have died. So, *If* there is some protection, it certainly is not 100%.

It has been difficult to determine accurate information in a situation where there was no historical knowledge of this particular germ. As new information has emerged, the guidance has changed—

sometimes several times! That is confusing and disconcerting to us and can lead to misinformation.

This infection and immunity to this virus has not functioned identically as other infections/viruses have in the past. Generally, getting to a point of "herd immunity"—with around 80% of the individuals who either have been vaccinated or who have contracted the disease—pretty much controls further spread of the disease, but this has not been the case with COVID. It has mutated faster than we have been able to get to herd immunity.

"I think this is because polio survivors are fully aware of what damage a tiny virus can do to one's body..."

In addition, the immunity induced by vaccines or by having the disease decreases over time and fairly quickly. After initially believing that two doses of the Pfizer and Moderna vaccines or one dose of the J&J vaccine would confer sufficient immunity, we are learning that there have been several "breakthrough" infections even in those who have received a "booster." It may turn out that we need yearly doses like we do for influenza.

From my vantage point in mid-January 2022, this is what appears to be true:

- 1) The current vaccines may not prevent people from getting the Omicron or other future variants, but they *do* prevent the most severe infections and nearly all deaths, and
- 2) Omicron is highly transmissible, which means nearly all will be exposed to this virus at some point or another.

My hope is that contracting Omicron will lead to better immunity to other COVID variants. Perhaps this will get us to enough “herd immunity” so that COVID becomes endemic instead of epidemic/pandemic. I think the best we can hope for is that COVID becomes like the flu, with relatively small numbers of people becoming ill with it each year and very few severe cases requiring hospitalization or resulting in death.

A review of death statistics in the United States comparing 2019 (before COVID) to 2020 show that the age-adjusted death rate increased from 715.2/100,000 population to 828.7/100,000. (At the time of writing, the numbers from 2021 had not been finalized). New to 2020 death statistics, the third most common cause of death was COVID, with heart disease and cancer still being number one and two respectively.

Over two-thirds of the deaths reported due to COVID in 2021 in the U.S. were in people over the age of 65, with the greatest risk in those over the age of 85. Of course, those over age 85 were at significant risk of dying from other causes too! In fact, all of us over age 65 have an increased risk of death compared to those who are younger!

Some people have been hesitant to receive the vaccine due to possible side effects.

Humans seem to have a big need to assign a “cause” to bad things happening even if these events are sometimes purely circumstantial. It might sound absurd, but would we blame a person’s death from a car crash on the COVID vaccine if they had received it a few days prior to the car crash? Likewise, when we hear of a death in a person who has recently received a COVID vaccine, we need to

consider what their risks of dying from other “normal causes” would have been if they had not received the vaccine.

“.. the best we can hope for is that COVID becomes like the flu, with relatively small numbers of people becoming ill with it each year ...”

Most of the serious adverse side effects from the COVID vaccines like blood clotting problems and Guillain-Barré syndrome also can happen if a person gets COVID, the disease. The risk is *much* greater of contracting the disease if a person is unvaccinated than it is for experiencing a severe adverse reaction from getting the vaccine.

There is and was a very small risk of developing paralysis from polio from the oral polio vaccine (4–5 cases per one million doses given), but for most of us polio survivors and our families, that did not deter us from lining up for those sugar cubes in the 1960s or getting our children immunized with oral polio vaccine! (Note: Oral polio vaccine has not been used in the U.S. since 2000.) ■

Post-Polio Syndrome: Adaptation in a Three-Story Townhouse

Mark Mallinger, PhD

My wife and I, both in our mid-70s, were faced with a life changing decision in 2018. Do we remain in the townhouse we've loved for 40 years or consider moving, in the near future, to a retirement complex? Living in a three-level condominium as my symptoms of post-polio syndrome began to mount suggested it was time to move. Our home offers everything we want, including location, view, space, comfort, esthetics and many other positive aspects, but climbing three flights of stairs many times each day was starting to present a challenge. We visited several senior living sites, all of which had many positive features, but were we ready to give up our much-loved home?

Although I was able to maneuver the steps from bottom to top (32 to be exact), I had been relying more and more on the bannister to help boost me up the incline. So, we began our search for a solution. We immediately dismissed a stair-chair type of motorized lift. Given the angle of our stairs, it would have been slow and awkward.



Another possibility we considered was to install an elevator, but the costs, complexity of installation and space required made this option impractical. At that point, we held off the decision to consider a future move hoping other possibilities would emerge.

In 2019 we discovered a modified elevator—actually a vacuum tube

that requires no hardware other than a 220-electric connection. It operates on the same principle that banks and retail stores used years ago as a way to move money and invoices through an air suction system. We pursued the research and discovered a supplier in our area. We visited the showroom and had the opportunity to try out the system in person. The ride was smooth, relatively quick (not bullet train quick, but much speedier than a stair-chair) and comfortable.

At that point we were ready for the next step, so we invited a contractor who specializes in the installation of the “elevator” to take measurements to explore the reality of fitting the device in our house. Luckily the design of our stairs leaves an open area in the center that would allow the vacuum tube to be placed in what had been unused space and would still allow us to use the stairs. The “tube” would operate in the area surrounded by the steps.

Our decision regarding where we would live, at least for the foreseeable future was made—we would remain in the townhouse indefinitely, or until further complications associated with age and PPS emerged. No construction was required, only the installation. The effects of COVID, however, postponed the process for some time. But, finally, the vacuum tube was installed in the summer of 2021.

Although our elevator is a one-person affair, the tube does come in larger sizes—though our space could not accommodate anything larger than a single-person unit. The full cost came to \$50,000. Certainly an expensive commitment, but it allows us to remain in our home. A device of this size for two-story homes would be less costly.

An unexpected outcome of the installation of the tube is the ability to use it as a “dumb-waiter.” The first floor of the townhouse is off the garage, thereby allowing us to move shopping items from the car into the elevator without having to navigate the stairs. The kitchen is on the second floor. Returning from the supermarket, Costco and Trader Joe's, our loads of groceries now can be moved to the kitchen with ease rather than negotiating the steps with goods in tow.

In addition, luggage is no longer a hassle—moving bags from the third floor (site of the master bedroom) down to the garage now is an easy exercise. Laundry also becomes much less of a bother—the

washer-dryer located in the garage only requires a push of the elevator button to eliminate the hardship of carrying it down and back up.

Although this particular solution may not work for others, the message for polio survivors is that alternatives in adaptation are possible and should be

thoroughly explored and considered. It may take a while to recognize all of the options available, but seeking out possibilities before making a final decision will likely result in a better outcome. ■

My Experience with the VA

Donald P. Abrams

I had bilateral polio in August 1954. I was treated at Herman Kiefer Hospital in Detroit, Michigan, and subsequently at the Rehabilitation Institute of Detroit for the first year. After that, until the age of 18, I was treated by an orthopedic surgeon, Dr. Alvis D. Finch.

I had an Armed Forces physical in 1967 and took my medical records with me. I presented these documents to the examining physician at the Fort Wayne facility in Detroit. I remember him observing that my right leg was smaller than my left and that I had a dropped foot, as well. He also observed that my left arm was smaller than my right. I felt this should have disqualified me from service; the doctor felt differently. I was drafted into the US Army.

I reported to basic training at Fort Knox, Kentucky, in January 1968. I struggled mightily with physical training (PT), but my inability to complete exercises went unnoticed. When the final PT test was given, I finished very low in every event, but somehow moved on to graduation.

I was sent to Fort Belvoir, Virginia, for training as a depot level generator repair and rebuild. Upon completion, I was assigned to go to Vietnam. I was then sent to the 101st Airborne Screaming Eagle Replacement Training School for two weeks and ultimately to Camp Eagle near Hue in I Corps. I spent a year with the 801st Maintenance Battalion,



Company A. We were wrenched tirelessly on broken gear with 10-14-hour days the norm, seven days a week in temperatures that could reach 110 degrees in the shade—except for monsoon season, when it cooled off but brought 12 or so inches of mud.

Physically exhausting? You bet! The only break from this was a three-day R&R at China Beach and a seven-day R&R with my spouse in Hawaii. The 801st received a Meritorious Unit Citation in 1969. I have a Bronze Star (meritorious), ARCOM (meritorious), National Defense medal, Vietnam Service Medal and Vietnam Campaign Medal.

Earlier this year I made a Veterans Administration (VA) disability claim for my post-polio syndrome (PPS) based upon the likelihood that the physicality of my service resulted in my current polio-related health conditions. I won't go into the details here. My physiatrist, Dr. Daniel Ryan, MD, was most helpful in writing a nexus letter with his diagnosis along with the opinion that my military service caused the onset of PPS.

As a veteran, I was able to search the archives of the VA for PPS claims. Searching back several years, I found that most were denied or remanded. Only two awards for PPS showed up. What I can't know is how many PPS vets were awarded disability without having to appeal. Though my disability claim was awarded without having to appeal, I'm pretty sure that PPS hasn't been recognized by the VA very often. Perhaps the groundwork was set earlier by others.

With precedent being set, I would like to pay it forward by reaching out to as wide an audience as possible and encourage other veterans with PPS to initiate a claim with the VA. ■

Question: *I consider myself to be fairly young for a polio survivor (I'm in my 30s). I would like to meet other polio survivors near me. There is a support group where I live, but I worry about the age gap and whether I'll fit in.*

Response from Rhoda Olkin, PhD:

Entering any group that knows each other can be intimidating. But there is much to gain in meeting and hearing from others who survived polio. And of course, you may find much in common, as well as several differences.

Having polio more recently and being younger than most polio survivors means that there are probably several differences besides current age. You might be from another country that received the vaccine later. Or you might be from a religion that doesn't endorse vaccines. You may be more mobile and active because of your youth, or you may be just beginning to experience and come to terms with some new symptoms of post-polio syndrome. You might be raising children who are still in the home, or be in your peak working years.

And being younger puts you in a different cohort than older folks. Many of us over 65 were raised in the era of "use it or lose it." We pushed ourselves hard, only to enter the more recent era of "conserve it to preserve it."

Having pointed out the differences, here are some of the similarities. Many of us experience pain and are masters of pain management. Some have histories of trauma associated with the polio onset, recovery and medical procedures. We know about relevant disability laws

and can spot curb cuts fifty feet away. Some of us use mobility devices, from canes to crutches to scooters to manual or electric wheelchairs. We fall into a generally higher income bracket than people with other types of disabilities and have higher rates of marriage. We use some "insider" terms such as "polios" or "chairs" (wheelchairs). We struggle as we age with signs of growing older, but we enter this phase with some expertise in workarounds and fall prevention techniques.

"... there is much to gain in meeting and hearing from others who survived polio. And, of course, you may find much in common, as well as several differences."

I can appreciate the worry about fitting in (I worry about this and I'm the same age as many people at the meetings!). But I hope it won't stop you from going to meetings. There is little to lose (an hour or two) and much to be gained.



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: *I think I'm experiencing a bit of pandemic fatigue. I know that I don't have many good years left to travel and be active, yet I realize it's not very safe to do so right now. I've seen many of my friends return to normal life even though cases are still high. I don't think I'm ready to do that, and it's causing me a lot of anxiety.*

Response from Stephanie T. Machell, PsyD:

It sounds like you're afraid that by the time you feel it's safe to travel and be active, your good years for doing so will be completely, or nearly, gone. It also sounds like watching your friends getting on with their lives is causing you to feel like you're missing the fun you imagine them having, and that wondering when you'll feel ready to join them and/or berating yourself for not being ready is making your anxiety worse.

People's risk tolerance varies. Unlike you, your friends are comfortable with the risks involved in returning to "normal" life. Because risk tolerance is a personality trait, it is unlikely that you can change yours.

It's hard not to focus on all you wish you could do, everything you miss doing, and when things will return to "normal," especially if you're also focused on how many "good" years you will have left when it does (something it's unlikely you or anyone else actually knows for certain). Shifting the focus away from these things is unlikely to get rid of all your anxiety, but it will reduce it. Rather than trying to force the worries away, accept them as normal during uncertain times and let them be. Or write them down and save them for a scheduled "worry time" of 15 minutes each day.

Then put the focus on what you can enjoy right now. If you're tired of your usual routines and activities, try something new. There are a multitude of virtual options available, including concerts,

theatre and dance performances, lectures and classes on every topic imaginable, and groups for people with shared interests. There are even virtual tours that allow you to preview the places you might like to visit when that becomes possible. The skills needed to find and access these activities are well within the reach of even the most technophobic. If there are in-person activities that are within your comfort level, make time to do those.

Feeling more in control may help, too. If you haven't already, think about what would make you feel safe enough to resume specific activities. Consider whether the enjoyment an activity will provide is greater than the anxiety it may provoke and give yourself permission to forego those that make you uncomfortable. Don't allow others to pressure you or make you feel bad that your choices differ from theirs.

Also consider when travel might feel comfortable for you again, as well as whether there is any kind of travel that feels safe now. Use this time to research locations and develop itineraries. If your concerns about travel becoming more difficult are more than ageist and ableist assumptions, plan to take more difficult or extended trips sooner. If booking future travel now would help you feel better, look into cancellation policies and travel insurance.

And remember, the money you've saved not traveling during the pandemic may allow you to take the trip (or trips) of your dreams! ■

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.



Need Help Purchasing a Brace or Shoes?

PHI has a special fund to assist with the purchase of a brace or custom-made shoes. The Joyce and Arthur Siegfried Memorial Fund provides grants of up to \$800 to assist polio survivors with out-of-pocket costs.

The fund was established in 2012 through an initial gift of \$7,500 from the Polio Network of New Jersey (PNNJ) in honor of Joyce and Arthur Siegfried, early advocates for the needs of polio survivors. Joyce Siegfried helped organize the first New Jersey Conference on the Late Effects of Polio in 1990, which led to the creation of the Polio Network of New Jersey in 1991.

Sadly, PNNJ recently decided to cease operations. Their legacy will live on, however, thanks to a sizable new grant to the Siegfried Memorial Fund. PHI would like to thank their president, Lottie Esteban, and the rest of the network for so generously providing for the needs of polio survivors wherever they may reside.

You can learn more about the fund and download an application at <https://post-polio.org/siegfried-fund/>. Or contact the office at 314-534-0475, info@post-polio.org.

Looking for Help Locating a Working PLV-100 Ventilator and/or Repair Manual

Mickie McGraw, Cleveland, Ohio

Since Respironics ceased production and repair of the PLV-100 ventilator, I have tried to adapt to their Trilogy ventilator (and several other models) without success. They are just not built to meet my needs and do not ventilate me adequately. I am currently using my last PLV and have no back-up. I do have a colleague who has experience in bio/medical engineering, who is willing to try to repair one of the ventilators I have, but he needs a repair manual.

Over the past year, I have been working very hard to find a used but functioning PLV, or at least a repair manual. I have gone online in this search and found some used ventilators on eBay and various other sites, but to date none have worked out in the long run.

Thus, I am reaching out to you—post-polio groups, polio survivors and their families, and respiratory equipment professionals—for your help in resolving this need, which dramatically impacts my quality of life. I know there are PLV ventilators out there and would deeply appreciate your help in connecting me to anyone who might be able to help.

Please contact me at mimaru79@aol.com. I would greatly appreciate any help or leads you can give me! Thanks so much.

Power Chair Available

PHI has been contacted by an individual who is looking to donate their Hoveround MPV5 to a polio survivor in need. The chair includes battery, manual and is in good working condition. Chair must be picked up in person in the Bluffton, South Carolina area. Please contact PHI (314-534-0475, info@post-polio.org) if you are interested.

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