

Post-Polio Breathing and Sleep Problems Revisited

Judith R. Fischer, MSLS, Editor, *Ventilator-Assisted Living*, and Joan L. Headley, MS, Editor, *Post-Polio Health*

“Post-Polio Breathing and Sleep Problems” was published in the fall of 1995 (*Polio Network News*, Vol. 11, No. 4). As a result of the continual flow of phone calls and emails from polio survivors and family members about this life and death topic, Judith Fischer, editor of *Ventilator-Assisted Living* (our other quarterly newsletter), and I decided to revisit and revise the original article. Our goal is to educate and to clarify misinformation about breathing problems of polio survivors. —Joan L. Headley, Editor, *Post-Polio Health* (ventinfo@post-polio.org)

New breathing and sleep problems in aging polio survivors can be insidious and often go unrecognized by either polio survivors, their family members or their health care providers. Polio survivors may have weakened breathing muscles as a result of the initial damage by the poliovirus; the lungs themselves were not affected. Those who were in an iron lung during the acute phase should be aware of the potential for developing problems later in life and educate themselves in order to recognize important signs and symptoms which may indicate underventilation which may lead to respiratory failure. Even those who did not need ventilatory assistance during the acute phase may also be at risk for underventilation and should be aware of problems with breathing and sleep.

Underventilation (hypoventilation is the medical term) means that not enough air reaches the lungs to fully inflate them. The result may be too little oxygen and too much carbon dioxide (CO₂) in the blood. Under-ventilation can be caused by one or more of the following: weakness of the inspiratory muscles (mainly the diaphragm and rib muscles) for breathing in, weakness of the expiratory muscles (the abdomen) for breathing out and producing an effective cough

to clear secretions, scoliosis (curvature of the spine), and sleep apnea.

Other factors contributing to a polio survivor's breathing problems are a history of smoking, obesity, undernutrition, and other lung diseases such as asthma, bronchitis and emphysema.

Vital capacity (VC) is the volume of air that can be expelled after taking a big breath and is a measure of how well the lungs inflate. VC normally decreases with age, but this decrease in VC is more serious in an aging polio survivor with weakened breathing muscles. Many polio survivors had impairment of their inspiratory muscles, and the normal changes due to aging may cause them to lose VC at a greater rate. Polio survivors may not experience symptoms of underventilation until their VC falls to 50% or less of predicted (normal).

Signs and symptoms of under-ventilation during sleep include:

- ◆ inability to breathe when lying flat — the need to sleep sitting up (orthopnea)
- ◆ inability to fall asleep and/or to stay asleep (insomnia)
- ◆ anxiety about going to sleep
- ◆ restless fragmented sleep with frequent awakenings

Thanks to Lisa Krivickas, MD, Spaulding Rehabilitation Hospital, Boston, Massachusetts; E.A. Oppenheimer, MD (retired), Los Angeles, California; and Mark H. Sanders, MD, University of Pittsburgh Medical Center, Montefiore University Hospital, Pittsburgh, Pennsylvania, for their reviews of this article.

continued on page 6

- ◆ shallow breathing or pauses in breathing
- ◆ awakening from sleep with choking sensation
- ◆ nightmares, night sweats, bedwetting or need to urinate frequently
- ◆ excessive daytime sleepiness
- ◆ morning headaches
- ◆ worsening mental status and impaired memory, concentration and cognition

Other symptoms may include:

- ◆ shortness of breath on exertion
- ◆ fatigue or exhaustion from normal activities
- ◆ claustrophobia and/or feeling that the air in the room is somehow bad
- ◆ general anxiety
- ◆ difficulty in speaking for more than a short time
- ◆ low voice/volume speech with fewer words per breath
- ◆ use of accessory muscles, such as neck muscles, to breathe
- ◆ weak cough with increased respiratory infections and pneumonias.

Polio survivors experiencing one or more of the above signs and symptoms should seek a respiratory evaluation (simple and noninvasive pulmonary function tests) by a pulmonologist, preferably one experienced in neuromuscular disorders. Physicians are listed in the *Resource Directory for Ventilator-Assisted Living* (www.post-polio.org/ivun/d.html).

Pulmonary function tests should include the following measurements. The values that indicate a warning sign for respiratory problems are in parentheses.

- ◆ VC — upright (<50%)
- ◆ VC — supine (a drop of >25% from upright to lying down)
- ◆ MIP — maximum inspiratory pressure (<60 cm H₂O)
- ◆ MEP — maximum expiratory pressure (<60 cm H₂O)
- ◆ peak expiratory cough flow (<300 L/min)
- ◆ end-tidal CO₂ (>45 mm Hg)
- ◆ overnight oximetry may be prescribed to detect episodes of oxygen desaturation (<88% during sleep).

Management of breathing and sleep problems can be achieved largely through the use of nocturnal noninvasive ventilation, commonly in the form of small, lightweight bilevel positive pressure units. The units have a long tube/circuit that attaches to a mask (nasal, facial or oral), nasal pillows or mouthpiece worn during sleep. Polio survivors may find themselves gradually extending periods of ventilator use, perhaps during a daytime nap. Some polio survivors may need to use a volume ventilator to guarantee delivery of a larger volume of air than a bilevel unit can provide. Noninvasive ventilation may eventually fail, and invasive tracheostomy positive pressure may be necessary.

Treating underventilation with oxygen therapy instead of assisted ventilation can lead to respiratory failure and death because supplemental oxygen

Question: *Why would my physician add oxygen to bilevel positive pressure ventilation, such as BiPAP®, if there is no underlying lung problem?*

Answer: It would be extremely worthwhile to request that PHI members who use a ventilator due to post-polio breathing problems ask that their physicians explain their oxygen advice so we can all benefit, or at the very least develop a list of justifications that can be reviewed. The question is simple and can be stated, “The use of oxygen for people with neuromuscular disease without any lung disease or pneumonia is a subject of considerable interest, and some controversy. Please explain why oxygen is advised as part of my post-polio treatment plan.” Send your physician’s comments to PHI (editor@post-polio.org).

A physician might advise adding oxygen to BiPAP® when there is no underlying lung problem, if the person is traveling by air, where the air has a lesser concentration of oxygen. Another possibility is that the bilevel device is not satisfactorily set up and not adjusted from time to time. If that is the case, the oximetry or ABG oxygen saturation might be below 95% and the physician might prescribe oxygen. The advised response to this, of course, would be to increase the IPAP (inspiratory positive airway pressure) to improve ventilation, and then to re-check the oxygen level until it stayed at 95% or better while using ventilation.

Reliable small portable oximeters, such as the Nonin Onyx® 9500, can now be purchased on the Internet without a doctor’s prescription. Having one at home to monitor assisted ventilation would allow minor adjustments of the IPAP as needed — if the treating physician agrees. Prices vary considerably on the Internet so search carefully. Most often an oximeter is not covered by health insurance.

Edward Anthony Oppenheimer, MD, FCCP, Member of PHI’s Medical Advisory Committee
Pulmonary Medicine (Retired, consultation only), Los Angeles, California (eaopp@ucla.edu)

Question: *I am a polio survivor who uses a ventilator during the night. My physician wants me to undergo a colonoscopy, but I am worried about anesthesia for this procedure. Should I proceed?*

Answer: A colonoscopy is an important test that can be performed safely on polio survivors who use assisted ventilation. In your case, I suggest a pulmonary evaluation before the procedure to document your respiratory reserve and a candid discussion with whomever is performing the colonoscopy. Sedation is needed because this procedure is uncomfortable. Usually a gastroenterologist does the colonoscopy with a nurse giving the sedation and supposedly monitoring the patient.

The colonoscopy should be done in a hospital (not an outpatient surgery center) with an anesthesiologist in attendance and administering the sedation. The procedure can be in the hospital’s GI lab or in an operating room. The GI lab has adequate monitors; someone (the anesthesiologist) needs to watch you closely and to be careful with sedation. Afterward, you can be observed for respiratory problems in the regular recovery room and, if necessary, go to a “monitored” bed for an overnight stay — one night should be enough. You can bring and use your own home ventilator, just be sure this is discussed with the hospital staff ahead of time. I have received this question several times and after dispensing the above advice, I have not heard of any problems.

Selma Harrison Calmes, MD, Member of PHI’s Medical Advisory Committee
Chair, Department of Anesthesiology, Olive View/UCLA Medical Center (shcmd@ucla.edu)

can blunt the function of the brain’s respiratory control center. However, polio survivors who use assisted ventilation and have additional medical problems such as COPD, pneumonia or heart problems, or who are undertaking long airplane flights, may benefit from oxygen therapy under careful supervision.

Polio survivors may also have sleep apnea contributing to underventilation. Sleep apnea, an interruption of breathing during sleep, can be obstructive,

central or mixed. Obstructive sleep apnea (OSA) is the most common form and is prevalent in the general population. The standard test for OSA is a sleep study; the standard treatment is the use of a continuous positive airway pressure (CPAP) unit with a nasal mask or nasal pillows during sleep. However, polio survivors with both weakened breathing muscles *and* sleep apnea should use bilevel positive pressure or volume ventilation, not CPAP. ●