

Survey of Health Professionals with Experience in Post-Polio Patient Care

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The most consistent comment to PHI for the last 30 years has been that “health professionals don’t understand.” We surveyed survivors about their health professionals in 2014. Those surveyed were connected with PHI, which may have skewed the results, but in general the picture they painted was not so dire. (See Post-Polio Medical Care: Post-Polio Specialists and Primary Care Physicians (Vol. 30, No. 4) www.post-polio.org/edu/pphnews/PPH30-4fall14p3-5.pdf.)

The next logical step was to survey health professionals who have experience in managing the care of polio survivors. PHI developed a survey with the assistance of Carol Vandenakker-Albanese, MD, Marny Eulberg, MD, Frederick Maynard, MD, and Martin Wice, MD — all physicians with 30+ years of experience.

The survey was distributed to health professionals in the *Post-Polio Directory* (both current and past) and through the *PHI Association Member Communiqué* and social media.

Who responded?

Fifty-two health professionals responded. Thirty were physicians. Twenty-two were allied health professionals, three were behavioral health specialists and one a massage therapist.

Sixty-three percent practiced in the United States. The other countries represented were Australia, Brazil, Canada, Denmark, India, Ireland, Korea, Nepal, Netherlands, Turkey and the United Kingdom.

Forty of the respondents were practicing professionals. The range of experience of the 52 was 2-43 years.

Fifty percent had ≥ 20 years of managing post-polio care. In addition, 62% practiced in a teaching hospital/rehabilitation center, 46% in an urban setting and 42% were in private practice.

Their practices

Practicing professionals reported seeing on average 101 patients a year (range 5–600), while retired professionals reported seeing 32 a year.

Sixty-four percent required/requires a referral to see them and 34% reported they always communicated with their patients’ primary care physician; 34% did if asked; 14% reported that they attempted communication.

Fifty-eight percent reported being part of a post-polio clinic; 66% described the clinic’s approach as multidisciplinary.

Training *(They were asked to check all that applied, so the sum is greater than 100.)*

Eighty-four percent received part of their training on the job/personal interest/personal reading; 38% at professional meetings (CME); 32% said it was part of their medical residency; 8% medical school (CME). Other sources of training were fellowships, post-polio specialist colleagues and survivors/patients.

Forty-three of the 50 said there is a need for more training about PPS in their specialty. Additionally, 49 of 50 said there is a need for continuing education about post-polio syndrome. The one dissenting opinion stated, “Continuing education implies that there is a large population of patients with this condition. It would be difficult to obtain such formats.”

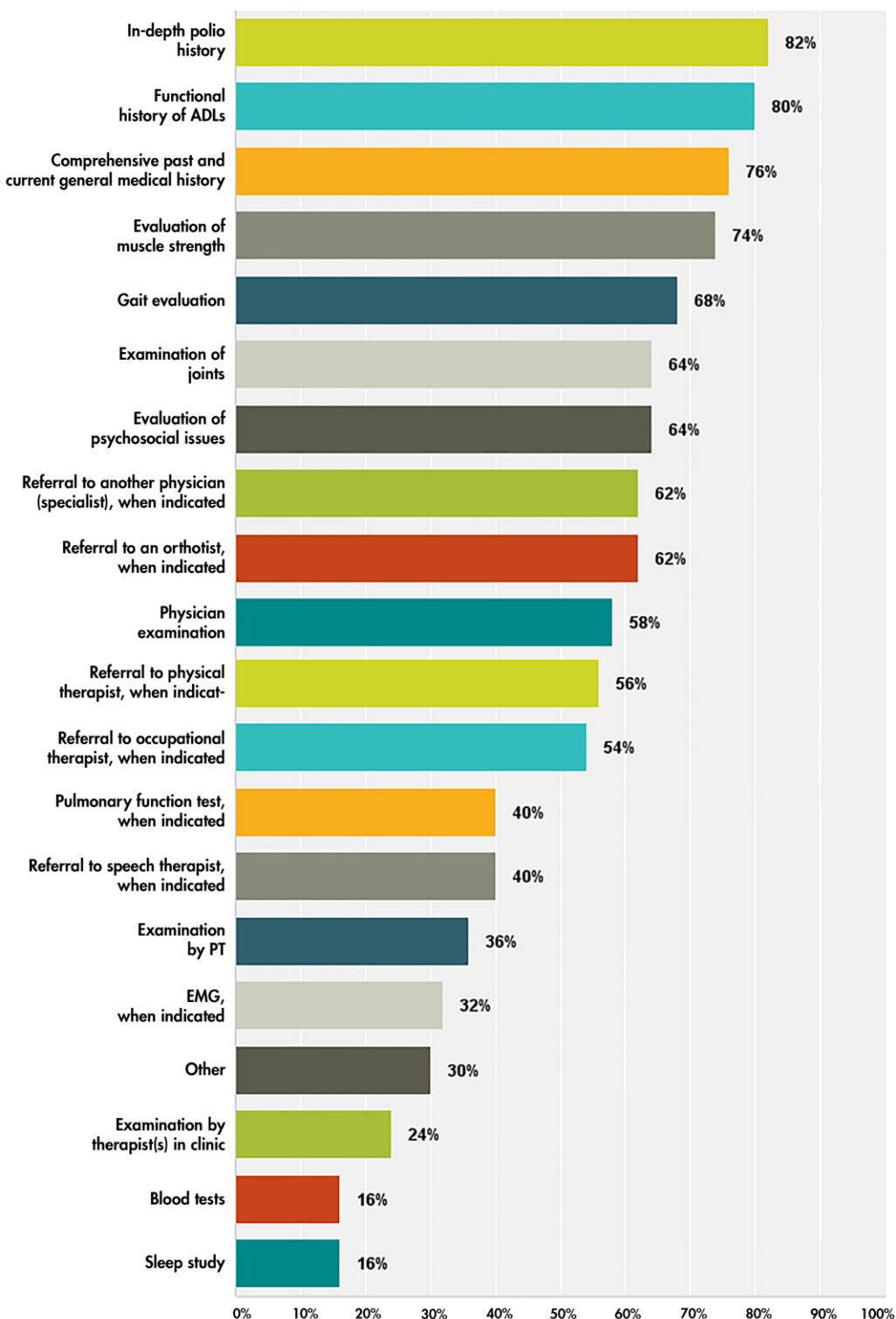
In ascertaining what training they provided, 66% reported that residents saw patients with them (38% some of the time; 28% all of the time).

Eighty-four percent reported that they lectured about post-polio syndrome, including post-polio seminars and support groups.

What did they tell us about treatment?

The following three charts depict information about the initial evaluation and the most common complaints and recommendations.

They were asked to check all is/was part of their initial post-polio evaluation.



They ranked the following classic complaints in order of most commonly reported:

		ranking							
complaint		1	2	3	4	5	6	7	Avg.
	Fatigue	22	7	8	10	1	1	0	2.27
	New weakness	4	18	12	6	8	0	1	3.00
	Pain	7	12	13	8	7	2	0	3.04
	Functional decline	11	8	7	14	5	1	2	3.10
	Chronic long-standing weakness	4	4	8	7	18	3	4	4.17
	Breathing	1	0	1	2	5	22	11	5.86
Swallowing	0	0	0	2	4	15	23	6.34	

The top 7 most common recommendations

Ranking	Recommendation	Most common placement
1	Patient education (referral to websites, support groups, books)	11 placed 1 st
2	Pacing advice	7 each placed 1 st and 3 rd
3	Exercise/Physical therapy	9 placed 1 st ; 8 placed 5 th
4	Mobility devices (canes, crutches, scooters, wheelchairs, etc.)	13 placed 3 rd
5	Bracing, lower extremity	9 placed 4 th
6	Counseling/psychological support	6 placed 6 th
7	Family education	6 placed 7 th

They were asked, “What complicates the management of the care of polio survivors?”

Co-morbidities (77%) were mentioned as the greatest complication in managing care. One professional pointed out the need to “learn differential diagnosis of depression vs PPS,” and not just the more commonly mentioned conditions such as osteoarthritis, hypothyroidism, spinal stenosis, fibromyalgia, etc.

Patient expectations were listed by 35% and “are often difficult to handle in my experience.”

Length of appointments, typically too short, was mentioned by 27%. It was noted that “complexity and uniqueness of patients requires customization.”

Other complications include:

- Older individuals with other physical, social and emotional issues.
- Lack of patient compliance due to past negative experiences with health professionals in the acute phase of polio disease.
- Inadequate access to medical records or accurate health history.
- Absence of objective evidence criteria, such as a biomarker.

What are/were the major challenges of managing post-polio care?

Many of the comments could be categorized into Emotional Issues, Education (lack of) and Funding, but also mentioned were:

- You can’t regrow an anterior horn cell.
- Lack of anything that really helps those with upper body issues.
- Sleep Labs do not monitor hypoventilation. There are very few physicians knowledgeable about respiratory insufficiency in PPS.
- Lack of evidence for successful interventions e.g., exercise or medications. Lack of expertise among orthotists.
- Avoiding the medical management model.

Emotional Issues

- Emotions of the patient in dealing with past polio and adjustments to new decline in function and stamina; affects identity.
- Each affected so different physically and emotionally and you must go carefully and work against their previous expectations.
- Patients' fear of the future.
- Helping patients make wise decisions for the future—"change management."
- Set in their ways and when they have problems, they may not be open-minded enough to try method B or C, when A no longer works.

Education (or lack of)

- Facilitating patient, family and caregiver education.
- Misinformation on the internet.
- Unnecessary testing rather than focus on health, behavior choices and function and people who prefer to "disable" someone rather than treat a correctable problem. ("Yeah, it matters that you are fat." Or abuse alcohol or drugs.)
- The patient leaves the polio clinic and continues treatment at home with less knowledgeable professionals.

Funding

- Not enough support for the management of patients (interdisciplinary team is the ideal situation).
- Inadequate healthcare coverage.

What advice would you give other professionals in your specialty about post-polio care?

The many thoughtful answers could be categorized into Process and Patient Care.

Process

- Make the commitment. Don't do a half-hearted job. Not "business as usual."
- Seek information and contact specialists. Share knowledge and experiences.
- Make a substantial collaboration with PM&R specialists; learn some basic rehabilitation medicine principles.
- Read books on polio and post-polio syndrome and the psychological implications, take continuing education courses, subscribe to *Post-Polio Health*, participate in post-polio support groups.
- Be willing to educate and to involve family as desired by patient.
- Understand the developmental issues related to age of onset of polio and of PPS, and what the cultural surround was at the time.
- Have a sense of humor. Be patient. Cannot cure or get them back to when young.
- Care of post-polio patients can be very rewarding. Patients are grateful for your expertise because they often have searched for someone to help them. Fabulous group of people.

Patient Care

- Stated many times: *Listen to the patient*. Each and every concern of post-polio patient should be taken seriously, meticulously and should not be neglected.
- Look at the whole person! Look for any other reason besides polio for symptoms.
- Ask about trauma associated with both the original polio experience AND related to the onset of PPS, including issues of mistrust in medical settings.
- Align expectations with their capabilities and activities.

- Be aware of exercise guidelines for post-polio patients.
- Treat each patient as unique. There is no cookie-cutter approach.
- Spend time on education. Communicate with patient.
- Be gentle, but specific.
- Really need to get to know the patient and meet him/her halfway. Incremental changes are better than any big changes all at once.

Bigger Picture Conclusions

Education and training of today's health professionals is happening. Much of the training is done in the academic centers where experts have the time to teach and also have access to students.

The responses to the survey emphasize the breadth of problems people who had polio are having and the need for a multidisciplinary approach.

The responses suggest a major focus is on mobility, which is a concern of many post-polio patients.

Behavioral health issues were mentioned several times indicating that health professionals recognize the need to pay attention to their patients' mental health.

In fact, the experts affirm the importance of post-polio health, including the physical, emotional, social, psychological and spiritual. ■